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ABSTRACT

A study examined the impact on parents when a young person with disabilities is involved in self-advocacy. Methodologies used included a literature review, interviews with nine families of young people with disabilities, collection of information about parent support initiatives, and discussion with a self-advocay group. During the course of the interviews, parents were asked how they felt professionals could be helpful and what they considered unhelpful. Positive experiences reported by parents included the following: having their experience and expertise as parents acknowledged, really being listened to, having access to professionals who have the right skills for the job, having their difficulties as parents really understood, and having a professional the parent can trust. Negative experiences reported by parents included the following: being asked to do fund-raising when what is needed is support for the parent, having professionals who look down on parents, professionals who do not keep their promises to help, and professionals who are in contact with a parent's family but not with each other. The report makes a number of specific recommendations to the various agencies and organizations involved with parents of young people in transition but first enumerates 12 principles underlying the recommendations, 10 of which are addressed to further and continuing education providers in England and Wales, and 7 of which are addressed to other organizations. A list of 41 references, a 16-item annotated reading list, 3 examples of parent support groups, a summary of the views of an advocacy group, and a brief case study of families and citizen advocacy are appended. (CML)

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Further Education Unit

Working Together?

A series of studies carried out for the UK contribution to the OECD/CERI Disabled Action Programme

Self-Advocacy and Parents

The impact of self-advocacy on the parents of young people with disabilities

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Working Together?

A series of studies carried out for the UK contribution to the OECD/CERI Disabled Action Programme

The OECD/CERI Disabled Action Programme

In 1978, the Centre for Educational Research and Innovation (CERI) of the Department for Economic Co-operation and Development (OECD) began work upon a major Disabled Action Programme. The initiative was supported by a grant from the USA Department of Education, Office of Special Education and Rehabilitative Services.

During the early part of the Programme, a number of reports on significant issues, including publications on integration at school and the transition to work were produced. Between 1982 and 1986, work on the theme of Transition to Adult and Working Life was undertaken and its outcomes subsequently summarised in the CERI publications, *Young People with Handicaps: The Road to Adulthood* (1986) and *Towards a Unified Concept of Transition* (1986), both of which offer a discussion of the many issues emerging from the Programme's activities.

Adult and working life

Recently the Programme has been concerned with aspects of adult life for people with disabilities, with a particular emphasis on preparation for employment. A conceptual framework was drawn up by the CERI experts that identified four key inter-related objectives for the transition of *all* young people; these were:

- employment, useful work and valued activity;
- personal autonomy, independence and adult status;
- social interaction, community participation, leisure and recreation;
- roles within the family.

Transition should be seen as a total process, that unites these aspects into a *coherent* whole but that is also *continuous* as a young person moves from school through continuing education and training, to work and independent living.

The last phase of the CERI project looked particularly at dimensions of transition, such as the changing roles of parents and the agencies involved with them and young people; preparation and support for employment; the part played by assessment; and the different criteria used by agencies in deciding who is eligible for programmes and services.

The UK contribution

The feasibility study

In 1988, the DES invited FEU to undertake a feasibility study for a

possible UK contribution to the CERI Programme. This was carried out within tight deadlines by Matthew Griffiths, National Education and Training Officer for MENCAP, advised by FEU, HMI and representatives from other national organisations. The findings of the feasibility study are summarised in Bulletin Number 1, *Transition to Adult Life for People with Disabilities* in the series of three that describes the UK work.

The findings of the feasibility study indicated that the development of inter-agency collaboration should be an important part of any UK work and that exploration of certain aspects of transition would form a valuable contribution both to special needs work in the UK and to the CERI programme. These aspects were:

- the role of new technology in supporting learners with special needs who were experiencing transition,
- the support needs of young people with disabilities and their employers during initial employment;
- the changing role of parents during transition.

The feasibility study also identified existing examples of innovative practice that would both benefit from involvement in the UK project and enrich its outcomes.

Working Together?

FEU was commissioned by the DES to co-ordinate and manage a contribution to the CERI programme, based on the recommendations of the feasibility study. Work on three major studies began in June 1988. Invitations to contribute were also extended to organisations involved in new activities that showed effective inter-agency collaboration in those areas of transition to be explained in the project.

The central principles

The project took three principles as central to its work:

- *that all young people have a right to adult status;*
- *that the empowerment of young people and their families was at the heart of this transition to adult status;*
- *that the role of professionals was to work together and with young people and their families to achieve empowerment and adult status.*

The series of studies

Three *major studies* were undertaken:

- *New Technology, Disability and Special Educational Needs*

  Tom Vincent, Open University

- *Enabled to Work: Support into Employment for Young People with Disabilities*

  Matthew Griffiths, MENCAP

- *Self-Advocacy and Parents: Self-Advocacy and its Impact on the Parents of Young People with Disabilities*

  Alison Wertheimer

In each of these studies, the experiences of young people with disabilities and their families, recounted by the people themselves, provide the starting point for analysis and recommendations.

Papers describing other innovative work were also included these were:

- *Access to HE: Students with Disabilities at the Open University* - Derek Child, Open University;
- *Self-Advocacy and Advocacy for Parents of Young People with Disabilities and Special Needs* - Philippa Russell, Voluntary Council for Handicapped Children;
- *Improving Employment Opportunities for Deaf People: The Provision of Vocational Training through the Medium of Sign Language* - Alistair Kent, RNID; Colin Hickman, Weald College of FE;
- *The National Council for Vocational Qualifications and Remploy: A Major Two-Year Project* - Elizabeth McEvoy, NCVQ/Remploy;
- *Education and Training: An Introduction to Some Education and Training Opportunities for Young People with Disabilities in the United Kingdom* - Deborah Cooper, Skill: National Bureau for Students with Disabilities.

The last three papers form part of the *Enabled to Work: Support into Employment for Young People with Disabilities* publication.

An associated project

An important FEU/REPLAN project was closely linked to *Working Together?; The Development of Self-Advocacy Skills with Long-Term Unemployed Adults with Disabilities through the Use of Portfolios*. This project examined the sorts of learning experiences that facilitated self-advocacy as well as the support and training needs of professionals who were developing self-advocacy relationships with their clients.

Common issues

The issues common to all the *Working Together?* activities are fully explored in the last of the three bulletins describing the project. They are outlined briefly here:

- the apparent paradox of *supporting empowerment*:
  - — what does this mean for individual professionals?
  - — how can services work together to make sure it happens?
- *the shift in power* during transition from professionals or parents to learner:
  - — what support do professionals and parents need to meet their changing role?

- the need for *continuity of support* for learners and their families during transition:
  - who provides this?
- the importance of *informal links and systems*:
  - how do service systems work together in a way that strengthens rather than supplants these?
- the vital role of *advocacy* during transition:
  - who has the opportunity to develop self-advocacy skills?
  - how can professionals plan for their development with young people?
  - what are the implications for families of young people involved in the advocacy movement?
- the importance of *assessment* in identifying both the *potential* and the *support needs* of people with disabilities as they move through further and higher education and into employment:
  - how can assessment be co-ordinated in the post-school years?
  - what sorts of systems most effectively meet individual needs?
  - should resources be allocated to individual learners or to an organisation?
- the need to transfer *instrumentality*, taking control, in one area of a young person's life to other areas:
  - how can agencies work together to facilitate this?
- the recognition that transition to adulthood takes time and that we generally give least time to those who need the most;
- the recognition that adult status can be lost or gained at any time in adult life; there are many transitions;
- the development of advocacy work cannot go on in a vacuum:
  - how can more real choice in the real world be made possible for people with disabilities?
- the difficulties experienced by young people, their families and professionals, when a continued need for physical care may seem to undermine much of the transition process:
  - how can services work together to support transition for *all* young people, regardless of their degree of *physical* dependence?

Each of these issues is addressed in *Working Together*? Good practice is highlighted and recommendations made that apply to education, health, social services and voluntary agencies.

inter-agency collaboration

Each of the studies examined the need for effective inter-agency

collaboration in their particular areas; but the management and co-ordination of the project itself revealed interesting lessons for collaborative work. These are discussed in the final bulletin in the Project series.

Inter-agency guidance and support for *Working Together?*

The whole of the UK contribution was supported by a Consultative Committee representing *21 agencies* either involved in the work or with an interest in the outcomes. Agencies from the statutory and voluntary sector were included, as well as those representing people with disabilities. Each of the major studies had its own steering group of experts in that particular field. Details of the Committee and steering group for this study are given in Appendix G.

The consultant to the UK Contribution was Matthew Griffiths, MENCAP.

Recommendations

Significant recommendations that should influence national and local policy are made in the three major studies of *Working Together?* Some are specific to a particular aspect of transition but others are common. Amongst the latter was one which FEU hopes to pursue in collaboration with other agencies; this is the piloting of a 'Kurator' or advocate system similar to that used in Denmark.

Other organisations will have their own priorities in the uses they make of this work. But, a word of warning; not all people with disabilities warm to the idea of inter-agency collaboration. They are not excited by the prospect of omnipotent multi-service intrusion into every aspect of their lives. What does inspire them is the development of their own power, their own right to speak for themselves, their own potential. *Working Together?* aims to further that development.

Pat Hood,
Project Director,
FEU

Further Education Unit

Self-Advocacy and Parents

The impact of self-advocacy on the parents of young people with disabilities

Further Education Unit

FEU aims to promote, encourage and develop the efficient provision of further education in the United Kingdom by:

- reviewing and evaluating the range of existing curricula and programmes;
- determining priorities and recommending improvements;
- carrying out curriculum, studies, development and evaluation;
- disseminating FE curriculum information.

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Foreword

All families experience a shift in their internal relationships when sons and daughters begin to test out their developing adult status. For most families it is a time of some anxiety and, often, healthy conflict.

In this study, Alison Wertheimer explores the issues that arise for parents when a young adult with a disability is involved in self-advocacy. She does this by enabling parents to speak for themselves about the changes happening in their families, their feelings about them and the professionals with whom they have contact.

The study looks at the implications for professionals, in educational or other settings, of the needs identified by parents during this time of transition. Consistent and continuous support that acknowledged parents as 'experts' in their own children was a priority. A real sense of partnership with professionals who were willing to take a role as facilitator and enabler was particularly valued. If parents were expected, and themselves wanted, to change the way they related to their young people, then professionals must reconsider their own relationship with parents; it can not remain as it was when children were at school. It is a time of transition for everybody.

The lessons for those involved in delivering a learning programme are also clear; parents need to know what you are doing and why you are doing it. Learning for independence can and should continue at home. When professionals are engaged in activities that may often 'trigger' adolescence and adulthood for young people, parent's legitimate needs for support and partnership must be met.

Parental anxieties about the growing independence of their young people are often based on hard-won experience of the attitudes and realities of the world into which their children will move as adults with disabilities. Professionals must work with that experience, not override it.

Parents can too often feel at the centre of conflicting advice and assumptions about the future of their child and their own role in that future. Agencies must work together, and with parents and the young person, agree on common objectives and complementary roles.

Finally, the study reminds us that self-advocacy is not something that happens on Wednesday afternoons for two hours; it permeates all teaching and learning activities wherever, and with whoever, they take place. Its impact on the lives of young people and their families can be enormous but unless the potential role of parents is recognised and their own transitional needs supported, only half the work will be done. Young people and their families will have been shown a vision of what

is possible but offered litte help in the day-to-day struggle to reach it. A first step for many of us would be to listen to, *and hear*, what the parent of a young person with a disability tells us.

Pat Hood,
Development Officer,
FEU

Alison Wertheimer

Alison Wertheimer is a distinguished freelance writer and researcher whose previous work has included publications for King's Fund, MIND and the National Federation of Housing Associations. She is a former Director of the Campaign for People with Mental Handicaps. Her latest book, on the experiences of people who have been bereaved by suicide, will be published by Routledge in 1990.

1. Introduction

The study: aims, outcomes and methodology

This study examines the impact on parents when a young person with disabilities is involved in self-advocacy. The emphasis of this particular study differs somewhat from other elements of the UK/OECD/CERI project since it looks mainly at the concerns of parents, rather than those of young people with disabilities.

However, although all the interviews were with parents, rather than with other carers, many of the issues which arose and which are discussed in Chapters 3–4, are relevant to the situations of other informal carers. Furthermore, paid carers who have perhaps looked after a young person over a long period of time (for example, in a long-stay hospital), may also face similar challenges when the young person makes the transition to adulthood.

Aims

Work was undertaken between January and April 1989 with the following aims:

- to examine the impact on parents where a young person with disabilities is involved in activities related to self-advocacy;
- to analyse the issues which are involved;
- to ascertain what resources are available to support parents in this situation;
- to draw up a series of recommendations for future action.

Outcomes

The outcomes of the study were as follows:

- a description of the case-study interviews which were carried out during the course of the study;
- an analysis of the issues for parents where young people are involved in self-advocacy;
- a set of recommendations for further action, including aspects of inter-agency collaboration that would support parents;
- a resource section with an annotated bibliography as well as information about existing initiatives which aim to support the parents of self-advocates.

Methodology

The methodolgy used in the study was as follows:

- a literature search and review of relevant material;
- nine interviews with families of young people with disabilities;
- collection of information about parent support initiatives;
- a discussion with members of People First of London and Thames self-advocacy group (see Appendix D).

Defining self-advocacy

What is self-advocacy?

A brief, popular definition of self-advocacy describes it as 'speaking up for yourself'.

The small, but growing, UK literature on self-advocacy offers some fuller definitions. For example:

> 'The brief definition of self-advocacy as "people being their own advocates and speaking for themselves" actually covers a very complex set of concepts. It includes the concepts of independence, freedom of choice, self-expression and group awareness.' (Cooper and Hersov, 1986)

> 'Self-advocacy is the act of making choices and decisions and bringing about desired change for oneself. In common parlance, it is defined as "speaking for yourself". Self-advocacy involves more than just talk, however. It implies the intent to produce change in one's life. It is this element of action which makes self-advocacy different from self-expression; for example, music, art and drama are all forms of self-expression unless performed with the intention to produce change. Any activity that involves self-determination can be called self-advocacy. This means that it includes simple acts, such as indicating whether you like the food you are given or not, to more complex actions such as choosing the colour of the shoes you put on in the morning or going on strike for higher wages. The range of decision-making and self-determination possible means that everyone can take part in self-advocacy at some level, regardless of the severity of their handicap.' (Crawley, 1988)

What are the aims of self-advocacy?

Involvement in self-advocacy may have one or more of the following objectives:

- putting forward and defending your own views;
- communicating your needs and wishes to other people;
- making choices for yourself;
- making decisions about things which affect your life;
- being assertive;
- having autonomy.

As the quotation above from Crawley emphasised, self-advocacy is about action, a point also mentioned by Williams and Shoultz (1982), who stress that self-advocacy is not only about learning to speak up about an issue and say how you feel about it; it also involves taking action to try and ensure that what you want to see achieved, does in fact happen.

The impact of self-advocacy on the lives of people with disabilities

Effective self-advocacy can enable people with disabilities to have greater control over their own lives, to become more self-confident and assertive, to experience greater self-esteem and to be generally less passive.

Self-advocates in the international *People First* movement of individuals with learning difficulties have expressed very clearly what they feel they have gained from speaking up for themselves:

> 'Self-advocacy has helped me to be a "self-doer", a decision-maker. Self-advocacy has given me self-esteem, built up my confidence and trust and confidence in myself.'
>
> 'People First stands for active involvement ... real jobs, respect, being seen as people with power over our lives, learning new things, making friends.'
>
> 'We can make decisions. We don't need to be talked at. Sure we need help sometimes — but not people telling us what to do.'

Although, as these comments clearly demonstrate, involvement in self-advocacy often confers many benefits, it is worth remembering too that self-advocacy can also be very hard work, and speaking for yourself may mean encountering opposition to your wishes and an unwillingness on the part of other people to let you have more control over your own life.

The impact of self-advocacy on other people

Promoting self-advocacy implies a willingness on the part of other people to offer the help and support which self-advocates require to enable them to put forward their own views and act on their own behalf.

Even more importantly, though, it involves other people such as parents and professionals having to recognise and acknowledge the power and control they frequently exercise over the lives of people with disabilities. Self-advocacy will almost always involve a change in the balance of power and control, and in the way other people relate to self-advocates. It may mean, for example, giving people with disabilities the opportunity to make choices for themselves, rather than making those choices for them. It may involve allowing people to take risks or to make mistakes as they learn to become more independent and autonomous.

On a more positive note, other people may learn to see people with disabilities in a very different light — as responsible adult members of society, as contributors rather than simply recipients and as individuals with abilities as well as disabilities.

Individual and collective self-advocacy

Self-advocacy may occur either individually or in groups and, as the following paragraphs indicate, young people with disabilities in the UK are involved in both these aspects of self-advocacy.

A person may advocate for themselves informally; for example, by choosing what clothes to wear when they get up or deciding where they wish to go on holiday; they may also be involved in more formal self-advocacy, by attending their IPP (Individual Programme Plan) meetings and playing an active role by stating their own wishes and objectives.

Collective self-advocacy may take place in groups such as *People First* (see below) or in other groups such as residents' committtees in group homes and hostels or user committees in day centres.

The development of self-advocacy in the UK

Participation conferences

The earliest self-advocacy initiatives in the UK were in the 1960s and early 1970s when a series of 'participation' conferences were held where people with disabilities were able to express their views on a range of issues including living options, employment and leisure. These events also enabled people with disabilities and others (mainly professionals and members of voluntary organisations) to spend time together, talking and sharing leisure activities on an equal basis — something which had rarely happened hitherto.

Self-advocacy in service settings

During the 1970s, self-advocacy amongst people with learning difficulties began to develop in service settings — mainly adult training centres, but occasionally in hostels too. A survey undertaken in 1980 (Crawley, 1982) found that 22% of ATCs had some sort of 'user committee'. However, only a small proportion of these groups were really active, e.g. taking part in staff training or being involved in decision-making in centres.

People First

A turning point came in 1984, when a group of people with learning difficulties attended an International Self-Advocacy Leadership Conference in the USA. On their return, they, and others, set up People First of London and Thames — an umbrella organisation for local groups — and in 1988, they hosted the second International Self-

Advocacy Conference in London, attended by over 300 people from the UK and abroad.

Self-advocacy in further education settings

Parallel to these developments there has been a modest but steady growth of further and adult education provision for students with special needs, including link provision, full-time provision, continuing education and outreach work (Dean and Hegarty, 1984).

Although curricula vary widely, many of the elements of self-advocacy as described above are being taught in further and adult education settings. This may involve learning specific skills related to self-advocacy such as assertiveness, decision-making or communication. Curricula may also focus on broader aspects of self-advocacy and independence such as vocational and independent living skills and mobility training. Various projects have developed detailed curricula for students with special needs, notably Hutchinson and Tennyson (1986) and Dee (1988).

Self-advocacy in the voluntary sector

Some organisations which have traditionally operated as groups working for, rather than with, people with disabilities have begun to offer facilities and support to people with disabilities to put forward their own points of view. Examples of this include London MENCAP's Participation Forum, the Spastics Society's Alpha Group and the Elfrieda Rathbone's 'Something to Say' project.

Some organisations have facilitated the work of self-advocates in other ways. The Campaign for People with Mental Handicaps (CMH), for example, has produced a series of learning materials for self-advocates (CMH, 1988).

A word about citizen advocacy

Citizen advocacy involves one person (usually, but not always, non-disabled) advocating on behalf of another person (with disabilities). The citizen advocate represents the disabled person's interests and ensures that their rights are safeguarded. Citizen advocacy represents a 'middle position' between self-advocacy and the traditional 'caring model'. The advocate is a vehicle, acting on behalf of the person with disabilities and helping them to achieve the objectives for self-advocates described above.

A small number of citizen advocacy projects have developed in the UK (Butler *et al*, 1988). Those presently in operation are mainly for people with learning difficulties, but one or two schemes have also been set up for people with long-term mental health problems.

None of the people with disabilities whose parents were interviewed for this study had a citizen advocate acting on their behalf; this is not altogether surprising as parents themselves frequently advocate for their

son or daughter (RADAR, 1988) and most people who have a citizen advocate at present have little or no contact with their parents. However, contact was established with the sibling of a man with learning difficulties who has been very actively involved in upholding her brother's rights and wishes, and this is described in Appendix F.

The impact of citizen advocacy on the parents of young people with disabilties who have their own citizen advocate is, as yet, a relatively uncharted area. However, as part of the research linked to the All Wales Strategy for Mentally Handicapped People, Dr Gordon Grant of the Centre for Social Policy Research and Development at the University College of North Wales will shortly embark on a study which will examine 'the impact of a pilot citizen advocacy scheme on people with a mental handicap and their families'.

2. The case-studies

The original aim was that the study should include interviews with up to ten families with a young person with disabilities. Within the limits of a sample of this size, it was hoped that the families would offer a balance in terms of:

- age and gender of the person with disabilities
- age and gender of parents interviewed
- a range of different disabilities
- a geographical spread
- families from a range of social backgrounds/occupations
- the inclusion of some families from ethnic minority groups
- a spread of different contexts in which self-advocacy is being practised

The families

Ten families were identified and contacted with a request for an interview, either directly or through key workers. In the event, nine of the ten proposed interviews were carried out.

The families comprised a random sample. They were identified mainly through members of the project steering group (see Appendix G.)

The three tables (Appendix A) provide brief details of the parents and the young people. As all interviews were undertaken on the basis that they were confidential, names have been changed to preserve anonymity.

Age and gender of parents

A total of 13 parents were interviewed, including four couples. Eight mothers were interviewed and five fathers. The average age of the parents was 53.5 years.

Age and gender of people with disabilities

There were ten young adults in the sample (one family has two daughters with disabilities): six men and four women. The age ranges were as follows:

- 16–19 years: 1
- 20–25 years: 7
- 26–35 years: 2

Range of disabilities

The disabilities and impairments of the young adults included: learning difficulties, brain injuries, hearing impairment (deafness), visual impairment (blindness), and physical disabilities.

Not all the disabilities had been present from birth. Stephen D had sustained brain injuries as the result of an accident nine months prior to the interview; Jane H had been born with a rare syndrome but had not become totally visually impaired until the age of 13; and Rajeev J's muscular dystrophy had been diagnosed when he was 7, since when he had become progressively more physically disabled.

Geographical spread

Although the sample size did not permit a wide geographical spread, families were interviewed in the following areas: London (2); Surrey (2); Nottinghamshire (2); Leicestershire (1); Northamptonshire (1); and Merseyside (1).

Ethnic minority group representation

Two of the families were from ethnic minority groups. The H family were West Indian and the J family were Gujarati-speaking (Hindu) Indians. (Both the young people had been born in the UK.)

The context of self-advocacy

The young people in this sample were involved in self-advocacy in a variety of different ways and in different settings. Seven people were currently involved in further education provision (on either a full-time or part-time basis) and two others had used further education provision prior to obtaining employment. Two people belonged to self-advocacy groups for people with learning difficulties and one person was active in campaigning groups of people with hearing impairments.

Methodology

All families were interviewed by the project worker in their own homes. Each interview lasted between one and two hours and a tape-recorder was used with the family's consent. Despite the relative brevity of the interviews, and the fact that families were only visited once, the material gathered proved to be very rich in content, and raised many different issues.

As mentioned above, the families were guaranteed confidentiality, and each family received a copy of the transcript of their own interview. It was agreed that it would be up to each family to decide whether they wished to share this with anyone.

A subject guide was used to conduct the interviews. Because the circumstances of each family were somewhat different it would not have been possible to use a structured questionnaire. The interviews

were basically conversations between the interviewer and the parents and subsequent feedback from some families indicated that parents had welcomed the opportunity to talk about issues relating to transition to adulthood.

Brief portraits of each family

Mr and Mrs A and Tony

Tony, who has an older married sister, lives at home with his parents. Diagnosed shortly after birth as having 'brain damage', he attended special schools, although the early years were marked by long spells in hospital for a series of operations.

After leaving school at 16, Tony had a brief period of work experience at his father's factory, which he enjoyed immensely, and both Tony and his parents were keen for him to get a proper job; they refused to consider a place at the local adult training centre. While trying to find employment, Tony's parents were directed to the local college of technology where he undertook a two-year link course, during which he learned various skills to enable him to become more independent; he also did further work experience, at a local supermarket. After the course started, Tony's tutor set up a highly successful parent support group of which Mr A became an enthusiastic member (see Appendix D).

After he finished the course in 1987, Tony managed to get a portering job in a department store, where his mother works, his post being partly sponsored by a national employment project which guarantees part of the costs of his wages on a tapering-off basis. Despite his success in employment though, Tony leads a rather restricted social life and usually only goes out in the evenings or weekends with one or other parent. His parents do not feel he is really capable of living independently and there are no plans at present for Tony to leave home.

Mr and Mrs B and Martin (interview with Mrs B only)

Martin lives at home with his parents, other members of his family living very close by; his grandparents live just up the road and his married sister also lives within walking distance. Martin was born with a hole in the heart and his hearing impairment was identified when he was nine months old. A pre-school home teacher of the deaf visited irregularly and Mrs B taught Martin as much as she could herself. At the age of eight Martin was also found to have mild cerebral palsy.

After attending two special schools, Martin went on to an FE college which, according to his mother, was a complete waste of time as it only taught him 'baby things'. He subsequently went to work at a market garden project for people with learning difficulties, and he also started attending another FE college on a part-time basis. Mrs B is much happier with this college, although she worries about some of the activities which she feels are risky. Mrs B's experiences of professionals

have not been very positive and she has often battled on alone; despite her own considerable physical disabilities due to osteo-arthritis. She does not envisage Martin leaving home at present.

The week before the interview, a 'crisis' had arisen when Martin decided he would no longer attend the market gardening project (for which he had been receiving £1.70 a week). He, his mother, his FE tutor and a social worker were to meet later that week to decide what should happen next, now Martin had made his own wishes clear.

Mr and Mrs C, Sarah and Gillian (interview with Mrs C only)

Mr and Mrs C have three daughters, the two youngest both being pre-lingually deaf. As the girls were born at a time when education for children with hearing impairments was, according to Mrs C, in something of a transitional phase, their early education took place in a number of different settings, including a private school for a small group of deaf children which was set up by Mrs C, a Montessori nursery school and a mainstream junior school.

Eventually though, both girls went to specialist schools for the deaf. Sarah, the older of the two, subsequently did a two-year design course and went on to work in computer-aided design before doing a post-graduate diploma. At the time of the interview, she was about to get married. Her younger sister, Gillian, having embarked on a home economics course after leaving school, recently switched to industrial design. She currently attends a college at some distance from the family home and in term-time, lives in a local authority hostel.

In one way and another, much of Mrs C's life has centered around disability and she currently chairs two national organisations working with people with disabilities. Although she would like to become more involved in other areas such as the arts, she feels that her knowledge and experience of disability will inevitably mean that she will continue to be involved in disability-related issues.

Mr and Mrs D and Stephen

Disability did not feature in the lives of the D family until seven months before they were interviewed for this study. With Stephen and his three sisters off their hands, their mother and stepfather were living their own lives. Mr D worked down the mines and his wife had just started her own wedding dress hire business. Stephen was living with his fiancee a few miles from his parents, and, as his mother described it, '[Stephen] worked hard and played hard'. One evening in July 1988, Stephen fell off a bar stool, sustaining head injuries from which he nearly died, and end up in intensive care.

He found being in hospital very disturbing, so Mrs D decided to take him home and care for him herself. This she did, until Stephen obtained a flat of his own in the city where he had been living before the accident. However, since he was unable to manage on his own, his

parents moved in more or less full-time to provide the care and support he now needs. They have spent very little time in their own home and, at the time of the interview, were about to sell the house.

Mrs D has had to give up her hire business and for both Stephen's parents, life has changed radically since last July. For the last four months Stephen has been attending a rehabilitation centre where he is making good progress although he still needs a great deal of support. He has also had to come to terms with his fiancee breaking off their engagement after a seven-year relationship. Fortunately for Stephen (and his parents) though, the circle of friends he had before the accident has stayed around, and because of this, Stephen has at least been able to maintain a social life which is independent of his parents. However, he remains dependent on them in other ways; they have now used up all their savings subsidising his £44 a week benefit which has to cover bills, food and entertainment. Stephen has made good progress since last July but his parents have been told it will be another year or more before they know the full extent of his recovery. At present they are living from day to day, not knowing whether they will need to support Stephen in the longer term.

Mr and Mrs E and Alan

Alan is the youngest of four children. Although a 'slow developer' his parents were not unduly worried and his problems were not identified until he started school, when his teacher informed Mr and Mrs E that she thought there was something wrong. At the age of seven, Alan was finally assessed as having 'brain damage'; his parents were asked to remove him from his ordinary school and Alan was sent to a special school. Shortly afterwards Mrs E met another parent of a child with learning difficulties. As a result, she says, she became very involved with 'the world of mental handicap', becoming welfare officer for the local parents group and running special clubs.

After leaving school, Alan had a brief spell in a sheltered workshop and subsequently moved to work in a timber yard, where he was employed for seven years. He left there when the family moved elsewhere to become co-managers of a residential project for adults with learning difficulties. Alan moved with them, became one of the project's residents, and, with his mother's help, found a job in an engineering works. He then changed jobs and began work in a horticultural scheme associated with the residential project. He also joined the People First self-advocacy movement and chaired a local group which was set up where he lived.

In September 1988 he attended the People First International Conference in London. At the end of 1988, Alan's parents had to leave the residential project at short notice; Alan has remained there, although he is working towards moving out to live more independently. He has also changed jobs, and on his own initiative, has returned to work in the timber yard where he was previously employed. Alan has a steady girlfriend, with his parents' support, and he hopes to marry her at some future point.

Mr and Mrs F and Sally (only Mrs F interviewed)

Twenty-five-year-old Sally, one of three children, lives with her parents — her brother and married sister having both left home. Although Mrs F suspected straightaway that something was wrong, Sally was not diagnosed as having cerebral palsy until she was 18 months old. After a brief unsuccessful spell of weekly boarding at the nearest school for children with physical disabilities, Sally became a day pupil and she remained there until she was 16. The next two years were spent at a residential college which, though beneficial, would have been more useful, her mother feels, if Sally could have gone there when she was slightly older.

After returning home from college, Sally attended a day centre in a neighbouring town for two days a week, the rest of the time being spent at home. More recently, Sally has been spending three days a week at a newly opened local authority resource centre for people with disabilities, and the other two days are spent at a computer centre for people with cerebral palsy, twelve miles away. Sally has now been accepted for an independent living scheme near the computer workshop she is already attending. She will be moving into a house with two other young women and they will be supported by a rota of six care workers. This will be a major life change for Sally and her parents, particularly her mother, who, at present, undertakes all Sally's personal care, usually goes everywhere with her daughter in the evenings and weekends and does much voluntary work, all of which is linked to people with disabilities. Both Sally and her mother are currently having to come to terms with these projected changes.

Mr and Mrs G and Michael (only Mrs G interviewed)

No-one was aware of Michael's difficulties until he started school, at which point he was assessed as having 'learning difficulties' and transferred to a special school. After leaving school, and following a couple of unsuccessful placements in sheltered employment, Michael started at the local adult training centre, where, according to his mother, although the contract work was boring and repetitive, and most other people were far more disabled, Michael apparently enjoyed himself.

About three years ago, Michael was one of a group of trainees from the centre who started attending an FE college two days a week. In the past year, he has moved to another college which he now attends as a full-time student on a special needs course. During his time at college, Michael has gained something of a reputation for speaking up for himself — and for the other students with special needs. He has joined a recently established self-advocacy group in the city and is also a consumer representative on a working party discussing services to people with learning difficulties.

Although he is able to go out on his own, Michael's social life is rather restricted and atypical for a man of his age. He attends a local Catholic

youth club and goes with his mother to a 'special' club for people with learning difficulties. Friends come round occasionally and sometimes Michael will go out for the day on his own. In terms of his future, Mrs G does not feel Michael is capable of holding down a job, and it seems likely that he will return to the adult training centre when he leaves college. Leaving home does not seem to be something which is being considered at all.

Mr and Mrs H and Jane (only Mr H interviewed)

The youngest of four children in a West Indian family, Jane was born with a rare syndrome which means that she is visually impaired, has had heart problems, has a tendency to obesity, and was born with extra digits. Her early years were marked by numerous hospital visits to correct some of these problems and, after initially attending a school for 'delicate' children, she transferred to a school for blind and partially sighted children. When Jane was about twelve her parents separated, since when she has lived with her mother; but her father only moved a short distance from the family home and has always remained in close contact with his daughter. In her early teens Jane lost her sight completely, although her father feels that she accepted her increased disability philosophically.

Since leaving school, Jane has been attending a residential college for students with visual impairment. She returns to her mother's home for college holidays, but is close to her father and spends part of every weekend with him. Mr H feels Jane has learnt to be more independent as a result of going away to college; however, she is due to leave this summer (1989) and he is unsure what she will do after that. At the time of the interview he had requested a meeting with the local specialist social worker, together with someone from the employment service, to discuss Jane's future. He hopes she will be able to earn her own living eventually and be as independent as possible.

Mr and Mrs J and Rajeev

Rajeev lives in a specially adapted council house with his parents and his older sister. No-one realised that there was anything wrong until, at the age of seven, he started falling down. Duschene muscular dystrophy was diagnosed and Rajeev was transferred to a special unit attached to an ordinary school. Over the years, Rajeev has become progressively more disabled and now uses a wheelchair all the time. Since leaving school, Rajeev has been attending an FE centre on a full-time basis. He has also recently applied to study with the Open University.

Because of his disability, Rajeev's parents have to attend to all his personal care needs, although he has become very heavy to lift and his mother can no longer manage this alone. Both parents are very attached to their son and would not contemplate letting him leave home, although they can admit that one day he may wish to do so. Mrs J does not want to contemplate the idea that anyone else could possibly care for her son and meet his needs. However, they are very

supportive of his educational activities and hope that one day he will be able to earn a living. Although caring for Rajeev is hard work, and their lives are in many ways restricted by having him at home, their religious faith — they are devout Hindus with a temple in their house — and their very strong sense of the importance of family life, which they feel is lacking in English culture, mean they would not consider changing their present lifestyle.

3. Discussion of the case-study interviews

As the previous chapter indicated, the circumstances and lifestyles of individual families varied widely. During the course of the interviews, however, common themes and issues emerged. This chapter discusses the main findings from the case-study interviews.

Past events and experiences

How parents cope with the transition to adulthood of their sons and daughters with disabilities will be shaped to some extent by the experiences they have had as their child was growing up.

How parents view the future for their son or daughter may be influenced by the sort of predictions they received when their child's disabilties were first identified. Mr and Mrs A, for example, were told immediately after the birth that their son would probably be deaf and blind — despite the fact that Tony has neither of these disabilities, and holds down a full-time job. But as his father says: 'We were very worried ... I never thought that he'd be employable, never in a million years.'

Sometimes parents were given a clear diagnosis but inadequate further information. This was the case for Sally's parents: 'It was left for the sister on the ward to tell me she was spastic, and I turned to my husband and I said "What does it mean?" and he said "Well, it means disabled, doesn't it?" And neither of us really knew.' Furthermore, they were not offered the chance to find out more from staff at the hospital, neither were they given any other contacts for people who might have helped them. They were only able to get more help and advice through their own efforts.

For other parents, though, the news that their child had a disability came much later on, so they had started out assuming that there were no problems and that their son or daughter would grow up normally. Parents like Mr and Mrs E and Mrs G, for example, had seen their children start primary school before being told they would have to leave and move to a special school.

Parents frequently mentioned that they had been offered little or no support from professionals as their child was growing up, with the result that they had simply decided to cope on their own and manage without other people. As Mr A describes it: 'We fought for whatever we got for [Tony] by ourselves ... we didn't want people poking their noses in.'

Sometimes this meant parents fulfilling more than just a parenting role. Mrs B, whose son is prelingually deaf, found that Martin's teacher

wasn't turning up so, deciding she had better teach him, she 'got stuck down and I had a go at it; I'd watched her do it and I thought right, here goes ... I practically learned him everything'.

Faced with this lack of appropriate professional support, parents may be forced to become the experts — as Mrs C found after two of her daughters were born with severe hearing impairment. Faced with confusing and conflicting advice about education, at one point Mrs C even resorted to setting up her own private school in the grounds of her house.

On the other hand, parental knowledge and expertise may not always have been valued by the professionals they encountered. Indeed, they can be made to feel they aren't doing a good enough job. As Mrs C recounts:

> 'Parents are made into scapegoats — that's an experience I've had even though I'm very articulate; you are always the one out there who's going to be blamed when things go wrong, you're the one [who is told] "You didn't do what I told you" or "You didn't follow my advice, and if you'd done what I said, it would have been alright". Professionals have excellent defence mechanisms [and] parents are very vulnerable to that'.

Parents may even be left with the feeling that they are somehow to blame, as Michael's mother found when he was 'playing up' at school: 'It was kind of, oh, [Michael's] done this. What are you going to do about it?'

Two families mentioned being somewhat resentful because, rather than feeling supported by staff at their child's school, they had been expected to support the school through fundraising activities. As Mr A said, 'All they were concerned about was bleeding fundraising'; so when his son's college tutor suggested setting up a parents' group, Mr A was, not unexpectedly, rather sceptical at first: 'I thought to myself ... I'm not going to get involved.'

Parental power and control

Many of the parents in this study still exercised a considerable degree of control over the lives of their adult sons and daughters — though sometimes this had very positive outcomes, such as when a parent was able to obtain employment for the person with disabilities.

Both Tony's and Alan's parents had been instrumental in finding them work experience and, subsequently, getting them into full-time open employment. When Tony was leaving school, it was Mr A who arranged for him to have work experience in the factory where he himself was employed. After Tony had subsequently completed a two-year FE course, his parents then managed to find him a job at the department store where Mrs A is employed. Alan's parents had also set up work experience for him, and, at a later stage, Mrs E helped him to find a job in a timber yard.

Some parents were also taking on the role of 'teacher' or 'trainer'. For Mrs D this was a major undertaking; Stephen had sustained brain

damage as a result of head injuries from an accident and three weeks after major surgery, Mrs D decided (against the hospital's advice) that she would take Stephen home and start the rehabilitation process on her own. She continued to do this, with her husband's help, until Stephen was accepted at a rehabilitation centre, nearly three months later.

Although Mrs C's daughters are now 20 and 25 years old, she still has to spend time 'working' with them. The morning of the interview, for example, she had spent the previous hour with her younger daughter, explaining about bank accounts and other financial matters. Because of her daughters' hearing impairments, time has to be set aside specifically for this sort of thing because lip-reading requires face-to-face contact.

Certainly some parents see themselves as the point where the buck stops. If they don't initiate or instigate, things just may not happen. Jane is in her final term of a two-year residential course for young people with visual impairment, and it is her father who has set up meetings with the local specialist social worker to discuss plans for Jane's future: 'I wanted to find out whether ... it was her or somebody else that would be able to point [Jane] in the right direction of training or whatever is available.' When the interviewer pointed out that setting up meetings like this involved quite a lot of work, Mr H just said: 'Oh well, you accept it.'

Mr A, likewise, saw himself as the person who was going to have to take responsibility for Tony's future after his FE course had finished: 'I thought, I'm going to have the bloody problem of what's going to happen to him after that.' In other words, parents know that in the end they will have to be the ones who initiate and instigate.

Parents like Mr A, though, did realise that in the end their control wasn't total. They would like Tony to go out more and develop a separate leisure life, but as his father says, 'Sometimes [Tony] just shrugs his shoulders as if to say "I'll do it if I want to do it. If I don't want to do it, that's it". Parents can only push so far! At the same time, Mr A realised that it was easy to ignore his son's very real achievements. Talking of Tony's job, he says: 'I mean, he's done it, not us ... sometimes we don't give our children ... enough credit ... I think we tend to put them down a bit.'

But not all parental intervention was as positive as helping people to find jobs and become more independent. Sometimes a sort of 'controlled independence' seemed to be present, where the person with disabilities was 'allowed' to be independent in some spheres but not in others: for example, employment was sometimes considered to be acceptable but moving from the parental home was not on the agenda. This was the case with Tony, whose father remarked that 'letting go is a very thin line, isn't it? You've got to ... push them away to a certain degree'.

This need to strike a balance in terms of independence was mentioned by Jane's father too: 'Generally we are protective, but realistically, you know; you know that you can't be there all the time for them so you want them to be as free and able to survive on their own as possible — so, you know, I would like to think that we give [Jane] as free a rein as

possible, as we think commensurate with safety.' Risk-taking is a major concern of these parents (see pp. 22-23 for a fuller discussion).

Because all the young people except one in this study were living at home at least part of the time, parents were in a position to exercise considerable control over their sons' and daughters' independence. Going out alone was often not considered appropriate by parents, despite the fact that some people were already moving around in the community independently when at college, for example. Martin is a case in point. Although he is able now to travel to college independently, he never goes out alone at other times, but is always accompanied by his mother or his sister, except when he goes up the street to see his grandparents. Mrs B realises he is capable of greater independence but admits, 'I'll not let him do it'.

Old habits die hard and sometimes the young people do very little for themselves at home because one or both parents have become used to doing everything for them; this was the case even when people were physically capable of doing more for themselves. As Michael's mother said: 'You are inclined to perhaps ask him to do something, and then the next time you think — oh, it's easier for me to do it because it'll be done quicker. You do get into that bad habit ... I think it's the pace of life ... you're just in such a hurry these days.'

Although only two of the ten young people in this study needed actual physical assistance with their personal care (e.g. washing, using the toilet), virtually all the other parents said that they regularly issued reminders about personal matters such as changing their clothes. The oldest person — 35 years old — was still being reminded to wash behind the ears!

In situations like these it can be difficult to ascertain just how independent a person actually is — or could be. What did seem clear though, was that people weren't always being given the chance to try and become more independent.

The impact of continuing physical dependency

As mentioned above, two people in the study (who were physically disabled as a result of cerebral palsy and muscular dystrophy, respectively) were living at home, where their parents undertook all their personal care including assistance with washing and toileting.

However, Sally's mother, Mrs F, and Rajeev's parents, Mr and Mrs J, were not seeking to hand over these tasks to other people. There were a number of reasons for this.

Sally, who has cerebral palsy and uses a wheelchair, has all her personal care needs met by her mother, although, at the time of the interview, Sally was due to move into an independent living scheme. It was not totally clear to the interviewer how much Sally could perhaps do for herself, but her key worker had been coming in in the morning recently to work on self-care skills. However, not only does Mrs F feel Sally cannot look after herself properly, but she also knows that she can do it herself more quickly: 'I mean, I can do it in 20 minutes, getting

her out [of bed] , getting her down here.' With her key worker, Sally was taking an hour or more. Routines built up over many years can be hard to change — and that can be the case for the person with disabilities too. Mrs F admits though, that maybe Sally 'would do more [with] other people bullying her'.

The continuing physical dependence of these young people denies them the normal personal privacy which young people would expect to have as they left childhood behind. As long as people like Sally and Rajeev remain at home, though, they have really no choice about who meets their personal care needs.

But even when, as in Sally's case, parents are offered the chance to hand over the physical care to other people, there may still be resistance. As her mother laughingly admitted: 'I suppose I think nobody else can do it like I can!' More or less the same sentiments were uttered by Rajeev's mother who, should her son wish to move into a home of his own, is prepared to move out with him (leaving her husband behind).

Rajeev's parents, who have always refused offers of respite care for him, both admit to having injured their backs with lifting their rather heavy son. But neither of them will consult a doctor about their back problems, presumably fearing that Rajeev might be taken away from them.

Sally's continuing physical dependence on her mother has had a considerable impact on Mrs F's own lifestyle. For example, like most other young people, Sally prefers to stay up late in the evenings (and lie in bed in the mornings), but, although her mother likes to go to bed earlier, unless she makes Sally go to bed, Mrs F snoozes in the armchair until Sally is ready to be helped into bed. Sometimes though, as already mentioned above, it was not altogther clear why people were not able to be more independent. Sally, for example, has an electric chair with a kerb climber, but although she can get to the nearby day centre unassisted, she never goes out alone otherwise. Her social life is totally bound up with her mother.

Privacy and confidentiality

During the transition to adulthood, most young people will increasingly confide in friends rather than parents, who hitherto may have assumed that they knew more or less everything about their children. The right to personal privacy is an accepted part of adulthood. However, where a young person has a disability and is using specialist services such as day centres or residential provision, this issue is often much more blurred.

Mrs E found this to be the case when Alan acquired his own social worker: 'The parent is going to feel — oh [the social worker] knows things about them that I don't know — and that's breaking the umbilical cord, isn't it, because you've always known everything about them.'

However, Mrs E had also worked in residential services for people

with learning difficulties and so had seen the issue from another perspective. She had, for example, been faced with the demand from one resident's parents that staff should inform them immediately if their daughter started a relationship with another person. This Mrs E had refused to do, since she believed that residents had the right to privacy in their relationships.

Services to people with disabilities have tended, until recently, to see parents (rather than service users themselves) as the people to be consulted. Although, for example, Sally attends her own IPP (Individual Programme Planning) meeting, her mother also attends, despite the fact that Mrs F is not wholly comfortable in that situation. 'They usually ask me if I want to say anything, and if there's anything I feel ... it's not always easy to say what I think in front of [Sally] though.'

An interesting example of self-advocacy and rights to privacy occurred with the parents support group which Mr and Mrs A attended at Tony's FE college, when some of the students demanded the right to attend the parents' meetings and hear what was being said about them. The parents' initial reaction was 'this is a meeting for us' — which raises the further issue of parents' rights to privacy and confidentiality. The students were eventually invited to attend but found the meeting 'boring' and elected not to attend again.

Parents' views on risk-taking

The issue of risk-taking loomed large in the interviews with parents, and mainly focused on people with disabilities either being physically harmed in some way or rejected by other people in the community.

For parents whose sons or daughters were using further education provision, this was an area of considerable concern, as the young person was, for the time being, out of their sight and beyond their direct control. However, although ignorance was not exactly bliss, some parents felt that as long as they didn't know too much about what was going on they could cope with the situation. This was the case with Mr and Mrs A when Tony was attending college: 'We used to say, when we heard afterwards, bloody hell! You know, we wouldn't have liked that — but if you don't see it, and you know they've done it — great'. Somehow, it was easier for parents to let other people initiate what they perceived as risky activities rather than doing this themselves.

This was echoed by Martin's mother, Mrs B: 'I don't care what you do when you've got him with you as long as you don't drop him in at the deep end ... I told 'em, what they do with him when they've got him, that's up to them — as long as they don't let me know they're doing it until after it's done ... because I'd make myself ill.' Indeed when she did know about Martin travelling independently as part of a further education input designed to increase his independence (because he left home alone that morning), 'I couldn't eat my dinner, I was thinking about him, wondering has he got there...'

Mrs F too, acknowledges that her daughter's independence training 'terrified' her — but also admits that she thought 'it did her [daughter] good'.

Stephen's parents, who had been used to their son being totally independent until his accident, had similarly divided feelings; as his mother says: 'Oh, I nearly had a heart attack — absolutely terrible, but I knew I'd got to let him do it.' Like other parents, risk-taking was seen as something of a necessary evil.

Although Michael had already been taught to travel independently while still at his special school, nearly 20 years later his mother still worries about him when he is out on his own. Her fears are perhaps more understandable, though, as Michael was attacked when out alone — although he was sufficiently competent to take himself off to hospital when it happened. Now she always waits up until he comes home — unlike her husband, who worries less about his son.

But Mrs G, paradoxically, feels there would be less to worry about if Michael was more severely disabled and unable to go out alone: 'Sometimes you feel you worry more about those [like Michael] that can just get out than, say, if you've got one [who] never leaves your sight. You know they can't do any harm or get involved in anything. I've always worried about [Michael] ... When he does go out I worry about him, you know — he'd talk to anyone, he's a very friendly boy (sic), very friendly'.

Parental worries about their sons and daughters moving around the community independently were, like those expressed by Mrs G, partly centred on a fear that they would get into the wrong sort of company, and might come to harm. Keeping your son around you, as Mrs B has tended to do, protects him: 'I'm his mum and he's my lad and I won't let anybody hurt him .. I just don't want [Martin] to get hurt, you know, 'cos there are people today who are very cruel, very cruel.'

Sometimes though, it was not so much the fact that the person might be actually harmed; it was more a question of their son or daughter possibly not being really liked and accepted by other people, such as colleagues at work — or do people just feel sorry for them? Mr and Mrs A discussed this with each other during the interview:

> Mrs A: All the girls love him at work, don't they?
> Mr A: Yes, but do they love him sympathetically, sort of thing?
> Mrs A: No, they love him.

Stephen's situation was slightly different; he was able to go out in the evenings and at weekends with friends he had known from before his accident. Even so, although this meant that his parents perhaps worried less than most of the other parents in this study, they were still concerned about his more general 'acceptability' by other people. His seven-year relationship with the young woman he had hoped to marry, broke up after the accident and the happy-go-lucky and popular young son they had known no longer seemed able to 'chat up the birds' as his stepfather says. Indeed, Mr D feels that Stephen has 'lost his personality'.

Markers of independence and adulthood

For most young people, the transition to adulthood has certain markers — moving out of the parental home and into some sort of home of one's own, establishing a long-term one-to-one relationship, having a social life and friends of one's own, being financially independent of one's parents, and having a proper job.

Of the ten young people in this study, only one person was actually living (full-time) away from the parental home, although two others were due to move into their own homes in the near future.

For some families, moving away from home was not being considered, even with someone like Tony A who was holding down a well paid permanent job. Martin's mother too would not consider her son leaving home, even though 'he's on about wanting a flat for himself … I says, no way, you're not moving out'.

Mrs B's solution was to arange for Martin to have 'a little flat in his bedroom — his own telly, video and computer … then he can please himself what he does'. Although this could not be equated with having one's own front door, it was a solution apparently favoured by several parents — the creation of a sort of 'pretend' independent living situation but safely within the four walls of the parental home. In fact, these rooms were more like a typical teenager's bedroom.

Rajeev's parents did not want to consider him leaving home. His two sisters would eventually leave home to get married and, as his father put it: 'After that, we can live three — [Rajeev], me and his mum.' They are, however, aware that Rajeev may one day want to move out, in which case, Mr J has decided, his wife would move out with Rajeev and Mr J would remain at home. A rather drastic proposal, perhaps, but they feel no one else could care for Rajeev and meet his needs in the way that they are able to.

At the time of the interview, Mrs E was adjusting to the recent separation from her son, Alan. Wearing her 'professional hat' as a residential services manager, she knows it is right (even though, for reasons outside her control, the decision was very abrupt), but: 'It's the first time in my life and [Alan's] that we've ever lived apart … but more than anything I don't want to interfere in [his] life and so he doesn't come up here very often — he just pops in and has a cup of tea … it's a very delicate situation.' However, despite this difficult and rather painful situation, Mrs E is still hoping that Alan will be able to move from the staffed house where he lives now, to a more independent setting with non-residential support. But even then she will admit that 'as a parent I would have awful problems with that'.

Mrs F is facing imminent separation from her daughter and, despite all her own feelings about the proposed separation when Sally moves to an independent living scheme, says: 'I know we've got to give her the chance to try — I hope it'll work out for her sake.'

Many of the young people in this study were leading very restricted social lives compared to their non-disabled peers. When they did go

out, it was often with one or both parents. Otherwise their leisure activities tended to be largely home-based.

Sally and her mother went more or less everywhere together — as Mrs F said: 'She doesn't really have a social life without us.' In fact, Sally does go out sometimes — to the PHAB club which she set up with her mother's help, to weekly swimming sessions for people with disabilities, and for meals — but always accompanied by one or both parents.

Michael's social life is similarly restricted — a weekly Catholic youth club (Michael is 35 years old) and a weekly club for people with learning difficulties, which he attends with his mother. Although friends from the training centre drop round occasionally, much of the rest of his leisure is solitary and home-based, e.g. watching TV.

Some parents, such as Mr H and Mr and Mrs A, were keen for their adult children to acquire a more independent social life. Mr H, for example, mentioned that he hoped that Jane, who has a visual impairment, would acquire some non-disabled friends: 'I think it can be a retardation (sic) if you just have people with difficulties as friends.'

In the evenings and at weekends Tony mostly only goes out with his parents. He has joined the same social club as his father and they go there together once a week, but Tony refuses to go on his own. Mr A is unable to resolve this: '[Tony] comes out with me once a week; I mean, I could take him out more often but I won't — on purpose — because I've always maintained I'd like him to do it himself.' But neither does Mr A feel he can ask anyone else to accompany Tony to the club: 'I mean, you can't ask people to take him ... you couldn't ask, say, whoever he works with, "Would you take him here?" I mean that's just not on, is it?'

Although financial matters were not discussed with the families in any detail, Stephen's financial position had had a significant impact on the degree to which he was able to regain some of his independence and maintain a social life with his non-disabled friends. Because he had been earning good money before his accident and had been used to a fairly expensive social life (visits to clubs, discos, etc.) his parents were subsidising him quite heavily as he would have been unable to go out very often on the weekly benefits he received. At the time of the interview though, this had become something of an issue between Mrs D and Stephen's social worker, who felt that by subsidising Stephen, they were not helping him to become more independent. Mrs D, on the other hand, felt that having a normal social life with his friends was part of Stephen's rehabilitation and helped him to be more independent.

With few exceptions, close personal relationships outside the immediate family did not feature in the lives of these young adults. Of the ten people in the study, one person was about to be married (Sarah C) and another person was engaged (Alan E). Sometimes though, the person was actively discouraged from forming close relationships. Michael's mother for example, said that he had had 'a few [girlfriends] ... but we don't encourage it to be honest [because] of what it involves'.

Alan's parents, on the other hand, are very supportive of his engagement to Amanda, and hope that they will be able marry eventually and set up home together. In fact, Alan has been engaged before, again with the full support of his parents, but that engagement was broken off by his fiancee's parents who refused to contemplate their daughter's proposed marriage. As Mrs E remarked: 'No-one asked [the couple] what they wanted.'

Employment seemed to be the area where parents were most supportive and hoped for the greatest degree of independence. Three people were already in full-time open employment, and one person hoped to start work shortly. The parents of two people currently in further education hoped to see them employed in the future. The future of the other four was less certain. However, as regards those four people, only one parent felt that her son (currently in full-time employment!) would never be capable of holding down a job.

Looking across the range of these different 'markers' of independence, it would seem that these young adults with disabilities have difficulty in achieving adult status as it is traditionally defined. Some areas of independence and adulthood, such as employment, seem to be more acceptable to parents; other areas, such as sexual relationships or independent living, are felt to be much more threatening.

Parents' perceptions of the adult status of their son or daughter

In the partial or total absence of some of the traditional features of adult status (see p.24), it can be hard for parents to see their sons and daughters as proper adults. Even with someone like Tony, who holds down a proper job, his father still says: 'I always say ... you are going to have an adult body with a child's mind.' The achievement of a single marker of adulthood does not always confer real adult status.

Where a person like Sally has a continuing need for personal care of the sort more often given to children (for example, assistance with washing and dressing), it can be a struggle for a parent to see the young person as a real adult. As Sally's mother admits: 'I suppose I still think of her as a teenager more, you know ... I mean, it's still like looking after a child isn't it, when you have to do everything for them?' (Sally, incidentally, is 25 years old.)

However, despite the fact that the majority of people in this study did not require that sort of direct personal care from other adults, it still seemed to be hard for parents not to treat them as children, for example, by constant reminders about washing, changing clothes, etc. 'Sometimes I forget that he is [an adult]; I say things like, don't do this, do that; and I think, you know, I forget.' (Mrs G)

The father of Jane, the youngest person in the study, is trying to come to terms with the fact that his 19-year-old daughter is entering adulthood. 'I'm sure it will change, because she's very independent; she doesn't want you to do things for her and I'm getting to accept that

now. You know, she's got to make her own way and [so] you don't try to lead and guide her all the time, but let her make her own mistakes.'

For Mrs E, Alan's involvement in the self-advocacy movement, People First, has helped her to see him as more of an adult: 'People [with learning difficulties] are like toddlers that have been kept as toddlers, and now find that they are not; they're grown-up adult people with a voice.'

In fact, many of the issues already discussed in this chapter will also have a bearing on how parents perceive their sons and daughters with disabilities. For example, negative messages about the future, which parents may have received when their child's disability was first discovered, may persist so that parents in this situation may find it almost impossible to see the young person as an adult. Similarly, a person's need for continuing physical care may be seen as incompatible with adult status. Finally, though, it is worth remembering that most parents find it hard to believe that their children have grown up!

Parental feelings about independence and separation

Achieving a degree of emotional independence from parents is usually considered an integral part of the transition to adulthood, but for most of the parents in this study, the idea of separation, of their 'child' becoming independent of them, was extremely painful to contemplate. 'I have mollycoddled him a bit, sort of wrapped him in cotton wool — and it's hard — it's hard to let go. I know I've got to do it, but it is hard, really … I've been his mother, teacher and nurse — and it's hard to break it off, you know … even now, big as he is, I'll sometimes say, "come, give us a love," and he looks at me as if to say "Oh no, not again".' (Mrs B)

According to Rajeev's parents, his continuing presence in the family home was central to their happiness and well-being: 'I want to see [Rajeev's] face every day. If I don't, I don't feel good.' (Mr J)

These feelings are not only experienced by parents, however. Although the young people themselves were not interviewed, it was clear, talking to some parents, that their adult children could also find separation difficult. Mrs F was aware that not only was she coping herself with the fact that Sally was shortly to leave home but Sally too had very mixed feelings about it: 'She [Sally] keeps on saying "I'm very nervous. I don't really want to go, but I know I've got to". It's all her own idea. So I said to [Sally], "You've got to make the break some time".'

Where the son or daughter with a disability remains at home, the emotional bonds are probably much greater than perhaps would be the case with brothers and sisters. As Mrs E said: 'Are family terribly important to the majority of people that move away from home? … They make their own family, don't they? Yes, [they] come back at Christmas and birthdays, and they know you're there but [they] are not in that same way dependent on you.'

Having been a residential care manager, as well as a parent, Mrs E had

seen the mutually painful feelings which can surface when a young person leaves home: 'We've had this trauma of people feeling their parents had put them in [Larch House] ... [and] you've got Mum and Dad still at home and you really want to be there more than anything else, but your mother and father desperately want the best for you ... they are going through a trauma of letting go, and they want you back and you want to go back.' Separation can indeed be painful.

Even when the young person really wants to be more independent, this can still evoke feelings of guilt: 'I think young people often have a lot of guilt feelings about wanting to be more independent... they're very torn.' (Mrs E)

However, not all parental feelings about independence and separation are so bleak. Tony's parents, for example, have found a real delight in his achievements. 'If you have [a] special needs child that has never done something and suddenly they've done it — you know, to me, that's great ... I tell you what one of the biggest surprises was in my life — when we first went on the phone and he was down in town and the phone range and he was on the other end ... I mean that's only a little thing but that to me was one of the biggest things.' (Mr A)

As Mrs E realised, parents can too easily collude with the rest of the world in seeing their children with disabilities as people with no abilities. 'We ourselves, and the public at large, have always said, "you're not capable" and it's wonderful to know that they are far more capable ... but that they just need more time.'

In some families there appeared to be little or no prospect that their lifestyles would change in the near future, as the young person wth disabilities would continue to live at home. Sally F, though, was about to move to an independent living scheme, Sarah C was shortly to be married, and Alan E had begun to live apart from his parents (who until recently had been managers of the residential scheme where he lived). These moves raised the question for some parents of what their future lifestyle would be like, now that they were no longer caring for a son or daughter at home.

Mrs C (who still has one daughter with a hearing impairment living at home) was the most positive about 'letting go': 'I actually want my children to be independent, you know ... I don't find difficulty in letting go at all, I think I'm lucky ... I think it's to do with wanting to get on with my life.' But, as she also pointed out, the reason for this may have nothing to do with the fact that she is the parent of two daughters with disabilities: 'I think that must be true of other parents — not just disabled parents. I certainly think it's impossible to generalise about parents [of children with disabilities] and overprotection is a stereotype.'

However, despite Mrs C's wish to 'let go' of her daughters, like many other parents in this situation she has become heavily involved in disability issues and organisations; currently she chairs two national disability organisations. Although she would now like to develop other interests, she realises this may not be easy to do: 'I'm never going to get away from it... [but] I'd like to pull out a bit.'

Mrs F, too, has spent many years heavily involved in organisations of and for people with disabilities — Crossroads, the local Access Committee, the PHAB club, the Red Cross, to name but a few! As she says: 'Everything I do is involved with disability and I sometimes think I'd like to do something completely different … it just seems as though you're surrounded by disability and you haven't got a life of your own.'

For other parents the future was even less clear cut. Mr and Mrs D's lifestyle had changed dramatically since Stephen's accident and, less than a year later, it was unclear how far they would be able to resume their former life; much would depend on the extent of Stephen's recovery, and whether he would be able to live independently in the future.

Although not all the interviews were conducted with both parents, several mentioned that they felt separation was harder for mothers than fathers — perhaps because it was often the mother who was the main care-giver, but also perhaps because the 'mothering instinct' is not just a myth: 'I think with all parents of a person with learning difficulties — and particularly mothers — we all find it good to be needed. I think the mothering instinct is there and when you have a person with mental handicap (sic), it always meets that need.' (Mrs E)

In Michael's family it is always his mother who stays up if Michael is out during the evening, whereas his father is happy to go to bed because, as he maintains, 'he's a big boy (sic) now, you know'.

For Mrs B, the bond is closer because of Martin's hearing impairment. His father has never learned to sign and, as a result, communication between them is often difficult and rather fraught. Perhaps as a result of this, Mrs B sees herself as 'mother, father, everything to him'.

Has the young person with disabilities been treated in the same way as other children in the home?

All the young people in this study had at least one sibling, although with one exception (the J family) none of the siblings were still living in the parental home.

Most of the parents felt that they had not raised their child with disabilities any differently from brothers and sisters in the family. Two parents, however, felt that there were differences.

Both Mrs C and her husband are university graduates and, she admits, they had to rethink things when their second and third daughters were born with severe hearing impairments. They had always assumed their children would follow their parents and go to university. Mrs C describes it in terms of having to build up a different set of expectations: 'I've had to acquire a framework, but a lot of parents of deaf children never really acquire [this]; they don't know what is reasonable to expect … I've had to rethink my priorities … but I still have to have high expectations.'

Mrs F is sure that she and her husband have raised Sally somewhat

differently from her brother, Simon, but feels that this is due to Sally's physical disabilities and her resultant dependence on her parents for personal care. 'I know you shouldn't [treat them differently]. It's because you have to do things for her ... I mean, I say to my husband sometimes: "You will treat her as a kid; you know you wouldn't do that with Simon."'

The differences may lie, partly, in the timescales of transition to adulthood. Parents in this study, whose children were all 19 and over, cited numerous examples of the sort of behaviours and situations commonly associated with adolescence — disagreements with parents, refusal to accept parental advice, not telling parents everything that they are up to, not wanting to help around the house, lying in bed in the mornings, and wanting to give up a job they don't like.

> 'I suppose it's the same with all youngsters. I found her very stubborn. She would only do the things she wanted to do and if she got an idea into her head, you couldn't change it ... she would take advice from her compatriots or her peers ... or from her teachers; she won't take advice from me ... or her mother. She thinks that whatever she gets outside is right and things we try and tell her ... are not right.' (Mr H)

> 'We went out on Sunday ... and he says, "I'm not going to work tomorrow". I says, "You are". "No", [he said] and he stuck me out, he wasn't going in; he didn't get up [the next day] so therefore he didn't go ... and I thought, well, I'm not arguing with you; you're old enough to know your own mind.' (Mrs B)

> '[Gillian's] not open at all; very secretive, never wants to tell you what she's doing or where's she's doing it ... [she] is a very strong character and she can be difficult.' (Mrs C)

What these parents can easily forget, of course, is that adolescent behaviour often is difficult, conflict-ridden and infuriating for parents!

Parents and self-advocacy groups

Two people were involved in the self-advocacy movement of people with learning difficulties. Alan and Michael both belonged to local self-advocacy groups, and Alan was also involved with the national People First movement and had attended their international conference held in London in 1988. Alan's local group had, unfortunately, folded, but he was still a member of People First.

Alan's mother, Mrs E, is a firm supporter of self-advocacy for people with learning difficulties and helped to set up a group in the residential project where Alan lived and where, until recently, she had been working. Mrs E felt that Alan had benefited considerably from his involvement in People First: 'It's given him confidence, and, I think, an opportunity that hasn't come [from] anywhere else; there's very few places that will listen to people with a mental handicap and I think this gives them the chance to form together, and together they've got to be heard ... I think [People First] has done a tremendous job.'

Mrs E felt that in the self-advocacy movement, people with learning difficulties could express their feelings about the way other people see them and behave towards them, something which perhaps parents were unable to do: 'I think People First can put that across; as parents we can't do that because it's too painful to say … but People First can talk about that.'

Michael's mother, Mrs G, was much more dubious about her son's involvement in self-advocacy. During his time in further education, Michael had gained something of a reputation for speaking up, both for himself and for other students with special needs; he also belongs to a self-advocacy group set up with the support of a local voluntary organisation. In addition, he attends meetings of a working group set up to look at health and social services provision for people with learning difficulties where he is one of the consumer representatives. But Mrs G worries about Michael's role as spokesman for other students: 'They go to [Michael] and say "I want this" and "Can we have that?", and I don't know whether I'm quite happy about that part really.'

Both parents mentioned various concerns they had about self-advocacy and the way it was operating. Mrs E was worried that maybe self-advocacy was developing too fast, with the result that people were placed in situations where they did not always have the necessary skills to cope: 'It's like learning to drive [on] an E-type Jaguar when really you needed to start with a smaller car. You've got all the power, you've got this voice that you never had before … it's like [Alan] being chairman [of his self-advocacy group]. He would love to be a chairman but he has to learn how to be a chairman.'

Both Mrs E and Mrs G were worried about the impact of self-advocacy on other people; when self-advocates perhaps lacked the necessary skills for self-advocacy. 'He wants people to hear him, even though he doesn't express himself in a way that is acceptable or in the same way as the rest of us do.' She hopes that 'maybe he would get a little bit of training that would help him to perhaps be more acceptable in taking his complaints and his feelings to the right people and doing it in the right way'. (Mrs E)

A further concern of Mrs G was whether Michael was able to get a proper grasp of the issues which were raised in self-advocacy. She thinks that sometimes he picks up the wrong ideas about things, although she did concede that sometimes what he said was right. She expressed general doubts though, about the capacity of people with learning difficulties to be effective self-advocates: 'I feel they don't really know the way the world goes on … I sometimes feel as though they're not intelligent enough to know what makes things tick.' This was echoed by a comment from Jane's father, who felt that sometimes his daughter wanted things which, in his eyes, were unrealistic: 'Although she tends to be quite independent, she probably has aims which are incapable of fulfilment.' (Mr H)

Parental involvement with further education

In the nine families (ten young people) in this study, four of the young people were in full-time further education, two were part-time, and three had previously attended further education courses. Only one person had no experience of further education provision.

During the interviews, parents were asked about various aspects of their own involvement with the further education colleges attended by the young people, including: contact with the college before and during the course, whether college-based learning was practised at home, and whether the college offered support to parents themselves.

Although the colleges or centres routinely made contact with parents before the course started, and most parents had attended at least one pre-course meeting, after that, with one or two exceptions, there was relatively little contact between tutors and parents.

Two of the families, which did have regular contact with the further education service, were visited by a social worker attached to the education service. Mrs B is visited regularly by Martin's tutor and a social work assistant: 'They never leave me in [the] dark on anything … 'cos she [the social worker] knows she daren't 'cos I get very worried.'

Similarly, Stephen's family has had regular visits from staff at the rehabilitation centre which Stephen attends for further education classes. Mrs D was very satisfied with the contact they had: 'They're very good, you know. They keep you informed what is going on and if I'm a bit worried about anything I just give them a ring; there's always someone there to talk to, you know, to talk it through. So I think, you know, they are very good.'

In his role as a parent governor, Mr H has regular and ongoing contact with the residential college for students with visual impairment which his daughter attends. However, although this means he meets college staff on a regular basis, he doesn't feel that governors' meetings really provide a forum where he can discuss his daughter's needs. Mr H's role is to represent the views of all parents of students attending the college, but, since the catchment area is very wide, he does not feel he is really able to do this properly.

Several parents mentioned that there were regular meetings at college specifically for parents but they were not always able to get to these gatherings. In the case of Mrs G, for example, meetings at Michael's college are held during the day and, since both she and husband work full-time, it is impossible for them to attend. Mr J had similar problems with getting to meetings; he works shifts as a bus driver, which means he can rarely get to evening meetings. Mrs C felt that she perhaps needed to be more involved and included in her daughters' further education courses than in their schooling, 'because there were things to be dealt with and sorted out … [but] they were so keen not to encroach on the autonomy of the young adult that they didn't bother to use you as a resource'. Both Sarah and Gillian C have done mainstream (i.e. non-special needs) further education courses and Mrs C has, in fact, been called upon to help college staff from time to time: 'it wasn't part

of the structure' but when the college was stuck and unable to find work experience for Gillian, as she says, 'they needed me', and she was asked to help.

More recently, she has also been involved with staff at the FE college where Gillian has been following an ordinary (non-special needs) course. When the question arose as to whether Gillian should continue with the course or not, the college, after obtaining Gillian's permission, contacted Mrs C and asked her to come to the college with Gillian to discuss Gillian's future. Although Gillian wanted to handle the interview herself, Mrs C discovered that the college has a policy of involving the parents of all their students — not only those with special needs. Striking the right balance of involving parents appropriately and usefully can be hard to achieve. It may be something which can best be negotiated by all those involved, i.e. parents, student and college staff.

None of the parents seemed to have been involved in any way in reinforcing college-based learning programmes, although at least one parent thought this would be a good idea. Mr H felt that because of the long holidays when Jane was home from college, she perhaps forgot what she had learned during the previous term. Home-based learning, he felt, might help to reverse that process.

Michael's mother had tried to get him to help with their own garden when he started learning about gardening at college but 'he'd get a bee in his bonnet that he wouldn't do it and that was it ... you'd never get him to do it'. Her attempts though, were not in response to a specific request from college that he should practise skills at home.

Mrs B had had an equally abortive attempt to involve Martin in cooking at home when he started a cookery course at college. She discovered that the college was using metric measures, which she didn't understand; as a result, she and Martin would end up arguing about whether or not she'd got the right measures when she tried to convert them! However, as with Mrs G, these efforts were not part of any structured programme of home-based learning.

Only one family had had the experience of belonging to a college-based parent support group. Alan's tutor had set up a support group specifically for the parents themselves and a description of that group can be found in Appendix D. This had clearly been a positive experience for Mr A who, according to the tutor who organised the group, benefited enormously from his membership of the group.

4. Discussion of the issues arising from the case-studies

Introduction

Any attempt to assess the impact on parents of a young person's involvement in self-advocacy will involve consideration of a range of issues. Self-advocacy, as the introductory chapter indicated, is a complex and multi-faceted concept. It involves speaking up and putting one's own point of view forward; but it is also about making decisions and choices for oneself, and about being an autonomous and assertive human being. Many of the goals of self-advocacy are linked to the achievement of adult status, and self-advocacy is one way in which people with disabilities can move towards adulthood.

Young people with disabilities are in some ways no different from their non-disabled peers; they are striving to become adults and to be recognised by others, including their parents, as separate and autonomous human beings. What these case-studies indicate, however, is that this task may be more difficult for them to achieve. Parents of young disabled adults play a much more central role in their lives than would usually be the case.

The growth of self-advocacy-related activities in further education and in groups like *People First* has provided young people with disabilities with increased opportunities to develop their autonomy and independence. However, as the interviews showed, there is often a reluctance on the part of parents to support and facilitate that process. It is likely to involve major changes in the family and to involve parents in painful feelings about separation and 'letting go'.

The transition from childhood through adolescence to adulthood involves two major tasks for the young person: the acquisition of practical skills which enable them to be independent in daily living, and the renegotiation of the emotional bonds with parents — to achieve 'linked distancing'. But negotiating the transition to adulthood is not only a task for the young peroople, it must involve parents too, who not only have to let go and separate to some extent from their children, they also need to redefine their own role in the family.

One of the most striking findings from this study was the generally low level of professional involvement with these parents of young adults (in contrast to the enormous growth of support services for parent of pre-school and school-age children). These parents were receiving little or no support to help them through the transition inherent in renegotiating their relationship with the young people and redefining their own future. As a result, although the young people were often beginning to develop limited measures of independence,

many aspects of their lives remained relatively unchanged because little was changing within their family.

The focus of this study is parents themselves and Chapters 4 and 5 will consider the following questions:

- What are the issues for parents?
- What are their tasks in transition?
- How can they most effectively accomplish these tasks — recommendations for the future? (Chapter 5)

What are the issues for parents?

In looking at the lives of these parents and their sons and daughters, what stands out most strongly is the degree to which their lives are bound up with one another. This finding is not new; earlier research has highlighted the close bond which commonly exists (e.g. Bayley, 1975; Devon County Council, 1978; Wertheimer, 1981; Richardson and Ritchie, 1986 and 1989).

But it is not just an emotional bond; it goes wider than that. Parents are virtually always the 'constant' in the lives of young people with disabilities, the ones who, unlike professionals, are not going to move on or move away. The parent is also seen in this light by services — as the backstop, the person who will pick up the pieces in a crisis, and the one who can be relied upon to respond in an emergency. As Brown, himself the parent of a child with visual and hearing impairment, says (1985): 'Parents feel they live their lives as responders, responding not only to the needs of child and family, but to every initiative, omission or decision of the authorities.'

However, the current growth in self-advocacy and advocacy may be beginning to challenge this position. Self-advocacy 'brings a degree of instability into the lives of carers as they begin to face taken-for-granted assumptions about their right to decide the future pattern of care for the person in the family, perhaps their own son or daughter, who is mentally handicapped'. (Grant, 1988)

As independent living becomes more of a real possibility for young people with disabilities, the fact remains that many parents see their role of parent as 'a job for life'. Card (1983), in a study of relatives of adults with learning difficulties, encountered frequent expressions of concern about independence training and 'an ardent wish to keep their relative with them'.

Card's findings are echoed not only in the experience of the families interviewed for this report, but in the research of Flynn and Saleem (1986) who found that amongst the group of young adults they interviewed, a significant proportion expressed a desire to leave home. However, 'pressures from family members to remain in the family home can be perceived as considerable'.

So parents are facing twofold pressures which challenge the status quo and which bring into question the assumption that parental support is a lifelong task.

The reasons why parents choose to continue in this role long after other children have left the family home are complex and will be different for each family. Undoubtedly though, there are benefits as well as disadvantages, despite the fact that parents frequently emphasise the negative aspects of their situation (Card, 1983). However stressful or difficult their task, it may provide them with a sense of purpose and a sense of identity; it may fulfil a need to be needed by others. A study of parents' views on 'letting go' by Richardson and Ritchie (1986) pointed to the 'compensations of caring' — the companionship, the shared humour, the general intimacy enjoyed in many of these families, and they went on to suggest that, in the absence of the normal emotional disengagement at adolescence, rather than weakening, the bonds between parent and child may in fact become even stronger.

A further feature of many of these families is the presence of well-established routines and rhythms of daily life, often built up over the years, and usually centred around the needs of the person with disabilities. This is well described by the mother of a young woman in her late twenties who was interviewed for Richardson and Ritchie's study (1989): 'We do the same routine, the same timing, the same thing every morning ... the same routine every day.' Anything which threatens to disrupt that routine can be hard for parents to even contemplate, as Cory Moore, the mother of a young woman with multiple disabilities describes (1988): 'For families like mine, anything that threatens the current routine is disruptive and unsettling to a sometimes startling degree ... [we have] made our adjustments ... we cope with daily rearrangements that the rest of the world can only guess at ... we focus on today ... we have difficulty thinking about the future and planning ahead.'

Hutchinson and Tennyson, while working with students with physical disabilities and learning difficulties, found this to be the case when attempting to develop the students' own self-care skills, commenting that, 'any attempt to disrupt these routines may well have far-reaching consequences for the whole family'.

However, it is worth remembering that change is something that all families with growing children have to face. Writing about ordinary adolescence, Herbert points out that for the young person as well as the parents 'all transitions involve some stress.

As families in this study and others (e.g. Johnstone, 1986) have shown, though, not only are the lives of these parents and their offspring closely bound to each other, but parents exert considerable control over the lifestyles of the young people.

One of the key tasks in the transition to adulthood is the establishment of a sense of identity (Pincus and Dare, 1978; Herbert, 1987; Soklov and Hutton, 1988), often involving the young person in experimenting with things like hairstyles, forms of dress and general appearance — and often resulting in considerable parental disapproval! For the young person with disabilities, this sort of experimenting may often not be allowed by parents. This may be done with the best of motives — to ensure that the young person does not 'stand out' and attract attention

to themselves — but it can prevent them from developing a sense of individuality and separateness from the family.

The issue of risk-taking is a major concern for these parents and has a considerable impact on the lives of the young people. Parental control is exercised in numerous ways, often because parents fear the consequences of allowing the young person greater freedom and independence. When the young person starts attending further education classes, this may become even more apparent. For example, the young peson may not be allowed to practise skills learned at college. As Dean and Hegarty have pointed out, learning can then become 'wasted effort', and may actually mean that staff and parents are working against each other (Simpson, 1984). However, this may not always be apparent initially, as parents may, in fact, give their approval to independence training but then refuse to allow newly acquired skills to be practised at home (Card, 1983).

Parents are not very explicit about what they feel these risks might be but their main worry seems to be that the young person will be harmed in some way — either by some event like a road traffic accident or by physical attack from another person. Parents may also worry that the young person will be the subject of negative and rejecting attitudes of the kind that they may themselves have experienced (Richardson and Ritchie, 1989).

Those young people whose physical disabilities mean that parents provide a high level of personal care with tasks like washing and toileting, would seem to have particular difficulties in establishing any sort of independence. In a study of young adults with physical disabilities, Thomas (1988) found that many of them had left school with very low levels of self-care skills and, even when independent self-care would not be possible, the young people were not making any decisions for themselves about how that self-care might be undertaken.

Thomas's findings are echoed by Judith Holman, a former university student with spina bifida. As she points out, when someone is 18 and parents are undertaking the sort of personal care tasks usually performed for a two-year-old, it can be hard for parents to see the young person as an adult. She goes on to suggest that this also has a 'spill-over' effect so that parents will treat the young person as a two-year-old in other spheres of life, making all sorts of other decisions for them, rather than allowing them independence in areas of life where this is possible.

But not all parental power is as negative or restrictive. There was also evidence from the case-study interviews that parents could be positive and powerful advocates; perhaps the best examples of this are the parents who went out and found the young people work experience and proper jobs. There was also evidence of some parents themselves taking on the role of teachers or trainers.

This key role of positive parental advocacy and support for the young person striving for independence was also noted in an American study of the relationships between young adults with learning difficulties and their parents. The authors (Winik *et al.*, 1985) found that the adults

who made the best adjustment to independent living in the community were nearly always those whose parents 'were supportive and who worked consistently to maximise their handicapped child's self-confidence and social adequacy'.

However, not all parents wish to take on this 'extra-parental' role, as one parent has pointed out: 'We must not strive so hard with parents to make them into teachers and therapists that they have no time left to be the one thing that they are most valuable at doing, being paretns.' (Fairbrother, 1985) This is something which individual parents will need to decide for themselves — but the choice should be available to them.

Any work with parents must take account of the fact that families with a young person with disabilities are not part of a homogeneous group; although, as the case-studies revealed, there were some common issues. The situation for each family will be different and parental attitudes to independence are likely to have been shaped by a complex set of factors, as an OECD report on the right to adult status (1988) emphasised: 'stereotyping parents of disabled youngsters is just as hazardous as labelling, for it implies that change and learning are not possible'; parents, the report went on to say, will have been influenced by a number of factors including how news of the disability was communicated, the attitudes of other people, etc. Attitudes to independence will inevitably also be influenced by the particular personalities of parents, irrespective of their experiences of being the parent of a child with disabilities.

How individual parents face the possible independence of their children will also be culturally determined to some extent. As a recent publication from the King's Fund points out: 'Ideas about adulthood and independence are often less sharply defined [in non-British] cultures]. Young people are encouraged to remain dependent until a much later age.' (King's Fund, 1988) For most young people, the transition to adulthood involves a number of different 'markers' which contribute to their adult status. Typical markets include: leaving home and establishing a home of one's own; marriage or settling into a permanent relationship; having a social life which is independent of the family; and entering full-time employment. But many young adults with disabilities currently do not have the opportunity to achieve these markers. What does the transition to adulthood mean for them — and for their parents? As one professional asked: 'Do we have a different concept for youngsters who are defined as having emotional and behavioural disturbance, or cerebral palsy or profound deafness?' (Madden, 1988)

Young people with disabilities may end up with, at best, a semi-adult status, like some of the people in the case-studies. Adulthood may have been achieved in the world of work, for example, but is someone fully adult who, despite going out to work every day, never goes out alone otherwise, has no real friends of their own and still lives at home? In situations like this, the transition to adulthood seems to have been only partially achieved. This will have an impact on parents too, who may

be involved in 'extended parenting' (Johnstone, 1987) at a stage when most parents would expect to have relinquished that role.

In typical adolescence, it is the young person who will initiate the proces of separation and differentiation from parents through assertions of independence, often marked by conflict and struggle (Pincus and Dare, 1973). For the young person with disabilities, however, the process may be more difficult and they may need to exert 'considerable force in order to break away from parents' protective behaviour' (Card, 1983). If unable to do that, they may do no more than express 'tentative hopes ... bound within the security of breaking parental rules rather than creating realistic personal aspirations'. (Johnstone, 1986).

Many young people, though, find support in their struggles for independence and adulthood in a peer group who will be facing similar challenges. Young people with disabilities, on the other hand, tend not to have a peer group of this kind (see Johnstone, 1986; Thomas, 1988). Even where people do have friends, they are often other people with disabilities who face similar difficulties in achieving independence and who cannot provide an appropriate role model.

If young people are to be enabled to become more independent, it is likely that other people — whether it is parents or professionals — are going to have to initiate and foster that process. But separating or 'letting go' is not an easy task for parents — regardless of whether their child has a disability. Writing about normal adolescence, Herbert (1987) makes the point that engaging in this process is like balancing on a tightrope; it involves parents in a supportive role while simultaneously requiring that they let go. Not only that, but transition for the young person means a transition for parents too, who are faced with redefining their own identities.

Many parents, too, have to face the fact that their adolescents may choose to adopt values, beliefs and lifestyles which differ markedly from their own (Soklov and Hutton, 1988). Separation can feel very much like rejection in those circumstances. Given the sorts of difficulties which parents of non-disabled adolescents face, it is little wonder that parents of young people with disabilities may not choose to instigate any transition to adult status. Because of the very close bond which often exists between the young person and parents (see above), any separation may be very painful for the young person too, who can feel torn between not wanting to reject a caring parent but wanting, at the same time, to have more independence. For young people with physical disabilities, where parents have always provided all the day-to-day personal care, this can be mutually painful, requiring, according to Thomas (1988), 'a great deal of courage for both a young person with disabilities to manage independently, and for the families to help them move towards living away from home'.

As much of the above discussion reveals, parents of young people with disabilities have a great deal in common with other parents, while there are also features which make their situation somewhat different. The tasks of adolescence for both the young people and their parents are essentially the same, but it seems that the presence of disability means

that more external supports may be needed — both for the young person and for the parents.

For many parents, the prospect of their child's transition to adulthood may reawaken earlier painful feelings; an American parent, Cory Moore, describes this vividly: 'life outside the boundaries that we and school systems have created in the past terrifies us. All our earlier feelings are reactivated. We may once gain experience grief and upset, guilt and sadness, fear and despair. *These feelings need to be acknowledged by the people who work with us'* (my italics).

Whatever the professionals may be saying about the young person's ability to achieve greater independence, parents may still be living with the messages they were given when their child's disability was diagnosed — not to expect too much, not to assume that their child would ever be 'normal'. Small wonder, then, if parents decide that they are not going to believe these new messages because they don't want to be disappointed again. Researching families with a person with learning difficulties, May and Hughes found (1988) that 'there would seem to be a widely held assumption of continuing dependency and a notable lack of enthusiasm for such fasionable concepts as "normalisation" and "independent living"'. Parents and professionals are often living with very different sets of beliefs and very different perceptions of the desirable future for young people with disabilities.

Yet professionals clearly have a key role to play in supporting both parents and young people with disabilities who are seeking to become more independent. As one self-advocate asked: 'If parents don't let go, who can help [people] to get going on their own?' (Cooper and Hersov, 1986)

However, as this study and others (e.g. Thomas, 1988) have revealed, parents of young adults may have little or no contact with professionals in health or social services. Thomas, for example, found that less than a quarter of the families had regular contact with a social worker — and of those families that did, over half were dissatisfied with the services they received.

Thomas's findings are echoed by May and Hughes who, researching families of school-leavers, found that 'just when their need for professional help and advice seems most pressing, they are likely to find themselves isolated and unsupported'.

In a study of further education services, Dean and Hegarty (1984) identified a similarly low level of professional involvement with parents which, they suggested, might be due to a number of factors including: a lack of tradition of home liaison in the further education service; students being perceived more as adults and therefore independent of their parents; and the amount of relatively new provision where staff had not yet 'got round' to parents.

Although parents in this study had very different levels of contact with professionals, they all had clear ideas about what they found helpful in their dealings with services and what they found negative and unhelpful (see Recommendations, Chapter 5).

What are the tasks of parents in transition?

As the discussion of issues above makes clear, parents have a key role to play in supporting the young person's transition to adulthood. For the young person with disabilities to achieve true adult status, parents have to involve themselves in the process of disengagement.

Some of the tasks facing parents will involve coming to terms with past events and experiences; others will be concerned with understanding the present situation and the changes which need to take place. And finally, parents will need to emerge from the transition, feeling not only that their son or daughter's future is assured, but that they themselves have a future.

However, these tasks will not only involve parents; professionals in a range of different services (education, health, social services, etc.), and parent organisations and groups, will all have a part to play in supporting parents (see Chapter 5).

Coming to terms with the past

- Parents need to feel that they have been 'good enough' parents and that the care and support they have given to the young person throughout childhood is acknowledged by those around them.
- Whatever their experience of professionals has been in the past, parents will need to accept that professionals can have a positive role to play now and in the future, both in their own lives and in the lives of their sons and daughters.
- Parents have, over the years, become the 'experts' on their children, and they need to have that expertise acknowledged and valued.
- Parents need to be able to let go of the defences against their perceived hostility of the world outside the family home if they are going to be able to let go of their son or daughter.

Understanding and working with the present

- Parents will need to understand the power and control they frequently exercise as parents and the impact this can have on the lives of the young people.
- Being a separate person and an individual in one's own right is an important part of being an adult. Parents need to understand that separation and differentiation are a necessary part of becoming a real adult.
- Parents need the opportunity to express their fears and anxieties about issues such as risk-taking, and to have those fears acknowledged and accepted in a non-jugemental way.
- Transition to adulthood is a normal part of growing up and parents

need to understand that their son or daughter is both capable of becoming an adult, and has the right to be seen as a person with adult status.

- Parents (together with professionals) may need actively to encourage and support the young person to develop more independence and autonomy.
- Parents may never have felt that their son or daughter would be capable of achieving adult status. They need the opportunity to explore what a framework for adulthood for young people with disabilities might involve.
- Parents need the chance to explore their own feelings about separation and letting go in a non-threatening and non-judgemental setting. They may choose todo this with other parents or with the support of prefessionals.
- The development of self-advocacy is relatively new in the UK and parents should have the opportunity to learn about what it involves, why it is important and the impact it can have on the lives of young people with disabilities.
- Parents, professionals and young people with disabilities need to be able to share their individual perceptions about the future for the young person. There are often marked differences in the way parents and professionals, and young people, view the future, and these different perceptions need to be acknowledged and shared.
- Parents may need to realise that the difficulties they face during the transition are not the sole province of parents whose son or daughter has a disability. Transition to adulthood can be painful for any parent.

Looking to the future

- Parents need to feel that they have a future of their own if their life is no longer to centre around the young person with disabilities. They will need to feel that they have a valued and significant role and identity in the future.
- Enabling and supporting the young person's transition to adulthood is likely to involve parents in both losses and gains. Parents need the chance to look at what their own particular losses and gains might be.
- Parents can continue to play an active role in the lives of the young people, particularly during the young person's transition to independence, by advocating for the young person. For example, this could involve campaigning for the development of high-quality services in the community and ensuring that the quality of those services is maintained and further improved.
- Becoming an adult does not mean severing all one's ties with parents (and other family members) and parents need to find ways

of developing a new (adult–adult) relationship with the young person. Becoming independent should not mean losing one's status as a family member.

- As young people move into adulthood, parents themselves will find their own lives changing. When children have left home, couples will often find they need to 'renegotiate' their relationship with each other.
- Even though parents may have many more years ahead of them, any discussion about the future of the person with disabilities is likely to force parents to confront the fact that they will not be around for their children for ever.

5. Recommendations

This report makes a number of specific recommendations to the various agencies and organisation involved with parents of young people in transition. Before spelling out the recommendations, however, there are a number of key principles to consider which should underpin all the recommendations.

Key principles

1) Any initiatives, such as parent support groups, need to recognise the individuality of these families. The homogeneous 'disabled family' does not exist — these families are 'families first'.

2) Services working with young people with disabilities and their families should be aware that the wishes and interests of young people and their parents may not always be synonymous. Professionals (including those working in education, health and social services) need to be able to work with these conflicts if and when they arise.

3) Support offered to parents needs to be continous and consistent in its approach.

4) Both parents and professionals need to recognise that they may have different views on a range of issues relating to independence for young people with disabilities. Professionals need to understand the reasons why parents may hold particular views about transition.

5) The parent and the young person are each entitled to privacy and confidentiality and those working in services need to acknowledge and respect that right.

6) Parents are likely to differ in the degree to which they wish to be involved in supporting the young person's move to independence. For example, parents who do not wish to participate in home teaching programmes should have their wishes respected.

7) Parents may wish to obtain advice and support for themselves, separately from any services or initiatives linked to the young person, and services should recognise that parents may have needs of their own.

8) Support for parents may be particularly welcome at key points in the young person's transition, such as when they are leaving school, leaving home or starting work, as these times are likely to be the most stressful and challenging for parents.

9) Support structures for parents should enable them to exercise some choice about how and when that support is offered. Some parents may prefer to talk to someone on a one-to-one basis, while others may prefer to meet in a group, for example. Some may wish to join parent self-help groups while others may be more comfortable with professionally led support initiatives.

10) Parents need to feel that they have a positive role to play in supporting the young person's transition to adulthood, and services need to recognise that parents can make a positive contribution.

11) A young person's transition to independence is likely to require the involvement of a range of agencies (e.g. social services, education, housing, health, DSS) and effective liaison and co-ordination will be essential.

12) All those involved in transition, including policy makers, planners and service providers, need to be aware of the conflicts on policy which exist at present. The broad commitment of government to informal 'care in the community' implies a continuing role for care by families which may conflict with a policy of enabling young people with disabilities to leave the parental home to live independently in the community.

Recommendations for further and continuing education providers

This section refers to 'providers' in an acknowledgement that further education for people with disabilities takes place in a range of settings and is delivered by colleges, adult education services or voluntary agencies.

1) Further and continuing education providers should be reflective about how their policies and programmes support self-advocacy by students.

2) Further and continuing education providers should draw up explicit policy guidelines relating to parental involvement. These guidelines will need to take into account the various aspects of parental involvement, including parents' support for students and the parents' own needs for support.

3) Whatever forms of parental involvement are developed, these need to have the full support of senior management and the necessary resources (including staff time) will need to be made available.

4) Job descriptions for tutors to students with special needs should include responsibility for developing parental liaison and involvement, although this would not necessarily mean that tutors were themselves initiating parent support groups or related activities.

5) The actual role of support tutors in relation to parents' own needs must be clearly defined. Tutors may be involved in parent support work directly or may liaise with others who could provide this

(e.g. the local social services department). It may be more appropriate for parent support to be offered by those outside the education service with the appropriate skills or for other services to provide this jointly with the education service. It may also be appropriate to involve other parts of the education services when students are based in a college of further education.

6) When considering the role of parents in supporting the young people's learning, providers should draw up policies which ensure that particular areas of concern to parents, such as mobility/transport training, money, and personal relationships, are addressed.

7) Providers need to draw up clear and explicit guidelines on privacy and confidentiality; for example, which student records (if any) are shown to parents and which remain confidential to staff and students.

8) Providers may wish to consider whether they can involve parents of former special needs students in working with parents of new and current students — for example, on courses, workshops and at open days.

9) Liaison with parents should include discussion of whether parents wish to become involved in home-based teaching programmes to reinforce learning that is managed by professionals. This may be a matter for negotiation with individual parents, but those who wish to become involved in this way should be supported in doing so.

10) Staff development programmes need to include some input on how tutors can work with families, what areas of conflict may arise and how staff can work with them. If education staff are to become involved in running parent support groups, staff development work should also include something about groupwork.

Recommendations for other organisations

1) A range of other organisations have a part to play in meeting the various needs of parents of young people in transition, including health and social services, parent organisations, self-advocacy groups and organisations, and local and national voluntary organisations.

2) The contribution of particular agencies and professionals should be based on their particular expertise and experiences. For example, national parent organisations might be involved in disseminating written information and initiating debate on the challenges for parents during transition.

3) Effective parental support will require efficient liaison between the various agencies involved, both at the level of individual families and at agency level.

4) Support for parents needs to start well before the young person leaves school and should be available to parents after the young person has ceased to use further education provision.

5) National organisations which support the development of self-advocacy (for example, King's fund, Skill: National Bureau for Students with Disabilities, MENCAP and CMH) should consider what role they can play in relation to parents of self-advocates. Possible activities might include disseminating written information, and organising conferences and workshops.

6) Self-advocacy groups, such as People First, should consider ways in which they can enlist the support of parents of self-advocates. Parents should be offered the opportunity to learn about the aims and objectives of the self-advocacy movement and to understand how they can offer appropriate support to self-advocates.

7) A range of strategies will be required for parental support and should be developed in response to what parents say they would find helpful. Support needs to be offered in ways which parents find useful and acceptable — for example, in terms of time, location, etc. Opportunities for individual support as well as groups are likely to be needed.

Recommendations for professionals

During the course of the interviews, parents were asked how they felt professionals could be helpful and what they considered to be unhelpful to them. Here is what they had to say, some of it based on their previous experience with a range of different professionals.

What helps — positive experiences

- Feeling a sense of equality with professionals.
- Having your experience and expertise as a parent acknowledged.
- Being able to use professionals who can take a back seat and act as facilitators and enablers.
- Really being listened to.
- Getting support when it is needed.
- Having access to professionals who have the right skills for the job.
- Being able to get the right advice when it is needed.
- Getting support for yourself (not just on behalf of your child).
- Being accepted for what you are.
- Having your difficulties, such as letting go, really understood.
- Being treated as an individual.
- Having a professional you can trust.

- Feeling that professionals are on your side.

  'I want someone to make a friend of me.'

  'She sits down; it doesn't bother her what the house is like or anything like that. She treats us like people — I hope she doesn't leave us.'

  'I think you've got to look after a disabled person day in and day out to know [how to look after them].'

  'It's very difficult to trust someone with what is very precious to you. I want someone to make a friend of me first, to win my confidence.'

What hurts — negative experiences

- Being asked to do things like fund-raising when what you want is help and support for yourself.
- Having professionals who look down on you.
- Professionals who don't keep their promises to help.
- Being blamed for your child's difficulties.
- Feeling devalued.
- Not having your feelings understood and accepted.
- Professionals who visit once, ask you what you want, and then don't come back again.
- Professionals who are always moving away or being promoted so that there's always a new person coming to see you.
- Professionals who don't consult you, but tell you what you should be doing.
- Professionals who don't give you enough information.
- Professionals who are in contact with your family but who don't liaise with each other.

  'Putting it frankly, our social workers have changed that many times we're getting a bit lost with them.'

  'See, I don't thing that [M] understands [my problem with letting go], with her being a "Miss".'

  'Parents [are] made into scapegoats — you're always the one who is going to be blamed when things go wrong.'

  'What's the point of asking for what we want? I get fed up. I say "leave me alone".'

Appendix A

Table 1: The parents who were interviewed

Name*	Age	Occupation
Mr A	49	Factory worker
Mrs A	50	Works in department store
Mrs B	44	Housewife (husband unemployed)
Mrs C	52	Magistrate, Chairman of two national disabilility organisations (husband: member of legal profession)
Mr D	44	Mineworker (redundant at time of interview)
Mrs D	44	Had own wedding dress hire business prior to son's accident
Mr E	59	Manager of residential project for people with learning difficulties (unemployed at time of interview)
Mrs E	56	Care manager of residential project for people with learning difficulties (unemployed at time of interview)
Mrs F	46	Housewife (former Crossroads care attendant)
Mrs G	59	Clerical assistant (husband: heating engineer)
Mr H	48	Accountant
Mr J	49	Bus driver
Mrs J	47	Housewife

* The names of all the families have been disguised.

Table 2: The young people with disabilities

Name	Age	Disability/ Impairment*	Occupation
Tony A	21	Brain damage	Portering in local department store
Martin B	19	Pre-lingual deafness and mild cerebral palsy	Attending a further education college
Sarah C	25	Pre-lingual deafness	Designer
Gillian C	20	Pre-lingual deafness	Studying on mainstream course at FE college
Stephen D	24	Brain damage following accident July 1988	Attending a rehabilitation centre part-time
Alan E	28	Brain damage/ learning difficulties	Member of People First. Works full-time in timber yard
Sally F	25	Physical disability (Cerebral palsy)	Attends resource centre, local authority (SSD) and computer workshop
Michael G	35	Learning difficulties	Attending FE college full-time
Jane H	20	Visual impairment	In final year of two-year FE college course (residential)
Rajeev K	20	Physical disability (muscular dystrophy)	Attending FE centre full-time

* Based on information given by parents.

Table 3: Parent-professional contacts

Family	Daytime occupation of person with disabilities	Residence of person with disabilities	Contact with professionals
A	Full-time job	With parents	None
B	Full-time FE	With parents	Visits from FE tutor and social worker
C	Full-time FE	LA hostel and with parents in holidays	Occasional contact with FE college
D	Part-time in rehabilitation unit	With parents attached to the unit	Social worker
E	Full-time job	In voluntarily-run home	None
F	Part-time in resource centre, computer workshop	At home (but shortly moving into own home)	Key worker, social worker, independent living scheme manager
G	Full-time FE	With parents	None
H	Residential FE	College (and with mother in holidays)	Local authority specialist social worker (SSD)
J	Full-time FE	With parents	FE staff and social workers occasionally

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Appendix C.
Annotated reading list

Bonnefin, V. and Brown, A. 'Loosening the ties that bind' in *Social Work Today*, vol. 14. No. 18, 11 pp 12-13, January 1983.

Describes group-work with mothers of teenagers with learning difficulties. The teenagers were socially isolated and the mothers were having problems in emotionally separating from their adolescent children.

Card, H. 'What Will Happened When We've Gone?' in *Community Care*, pp 20-21, 28 July 1983.

Report on a group of relatives who took part in a survey to ascertain their views on the future residential needs of sons and daughters with learning difficulties. Discusses the results of the survey, the reasons for the choices made, and the issues raised.

Cooper, D. and Hersov, J. *We Can Change the Future. Self-Advocacy for People with Learning Difficulties: A Staff Training Resource* (plus video) Skill: National Bureau for Handicapped Students, 1986.

Includes a useful introduction to the development of self-advocacy in the UK and a chapter on parents and self-advocacy.

Dee, L. *New Directions: A Curriculum Framework for Students with Severe Learning Difficulties* FEU/NFER, 1988.

Includes discussion of parental involvement with curriculum development and implementation, etc. Suggests a framework for evaluationg parental involvement.

Fairbrother, P. 'Needs of Parents with Adults' in Mittler, P. and McConachie, H. (eds.) *Parents, Professionals and Mentally Handicapped People: Approaches to Partnership* Croom Helm, 1985.

Written by the parent of a 35-year-old woman with learning difficulties, it discusses a range of issues including independence from parents, teaching programmes, rights, sexuality and bereavement.

Flynn, M. and Saleem, J. 'Adults who are Mentally Handicapped and Living with their Parents: Satisfaction and Perceptions Regarding their Lives and Circumstances' in *Journal of Mental Deficiency Research*, 30, pp 379-387, 1986.

Based on interviews with 12 people with learning difficulties, it was found that, despite increasing emphasis on independence training in FE and day centres, on the whole parents are reluctant to encourage this.

Griffiths, M. 'South Thames College: A Parents' Support Group — the Initial Experience' in *Educare* , No. 17, pp 22-25, May 1985.

Outlines the development of the college's first support group for

parents of students with special needs. Identifies the achievements of the group and lessons for the future.

Hutchinson, D. and Tennyson, C. *Transition to Adulthood: A Curriculum Framework for Students with Severe Physical Disability* FEU, 1986

Discusses the need for parental involvement and some of the ways in which this was developed on an FE course for students with physical disabilities and learning difficulties; suggests a framework for evaluation.

Johnstone, D. 'Post-School Life-Styles of Adults with Severe Learning Difficulties — Is There Life After 16?' in *Educare*, 25, pp 18-23, June 1986

Descriptive account of lives of a number of young adults who were interviewed about their life experiences. Looks at role of the family, friendships, personal responsibility and autonomy, leisure, ambitions and aspirations.

May, D. and Hughes, D. 'From Child to Adult: The Significance of School-Leaving for the Families of Young People with Severe Mental Handicaps' in Horob[illegible], G. and May, D. (eds.), *Living with Handicap: Transitions in the Lives of People with Mental Handicaps* Jessica Kingsley Publishers, 1988.

Based on a study of school-leavers; highlights the particular problems of their families, their isolation and general lack of support.

OECD/CERI *Disabled Youth: The Right To Adult Status*, OECD, Paris, 1988.

Describes the social and psychological difficulties facing young people with disabilities. Includes case-studies.

Richardson, A. and Ritchie, J. *Making the Break: Parents' Views About Adults with a Mental Handicap Leaving the Parental Home* King Edward's Hospital Fund for London, 1986.

Based on extensive interviews with parents; explores parents' views on this key issue and discusses the implications for policy and practice.

Richardson, A. and Ritchie, J. *Letting Go: Dilemmas for Parents Whose Son or Daughter has a Mental Handicap*, Open University, 1989.

Based on the same study as described in *Making the Break* (see above); provides a deeper exploration of the feelings of parents when considering 'letting go' of an adult son or daughter.

Simpson, B. 'Parents as Partners: Parental Involvement on the Linkways Course at Farnborough College of Technology' in *Educare*, No. 20, pp 13-14, June 1984

Describes a highly successful parent support group initiated by the tutor of a two-year links course for students with special needs.

Wilson, G. 'The Relationship Between Special Needs Staff in a College of Further Education and the Parents of Students with Moderate Learning Difficulties: Playing it by Ear' in *Educare*, No. 32, pp 3-12, October 1988

The results of a survey of parents whose 16-18-year-olds were

attending the Transition Course at Calderdale College; discusses parents' views on the course, and parent-staff relationships. Also includes a survey of relevant background literature.

Wimik, L. *et al.* 'Adult Mildly Retarded Persons and Their Parents. The Relationship between Involvemnt and Adjustment' in *Applied Research in Mental Retardation*, vol. 6, pp 409–419, 1985

Looks at the relationships of 29 adults and their parents; identifies three main types of relationship: supportive, dependent and conflict-ridden.

Appendix D. Examples of parent support groups

Farnborough College of Technology: Linkways Course (1983-1987)

Background

Farnborough College of Technology runs a Linkways Course for 16-19-year-olds with moderate difficulties. Students are mainly referred from special schools and the course aims to support students in the transition from school to adult life.

Reasons for developing parental support: aims and objectives

The Parent Support Group (PSG) was set up by Brian Simpson, Course Tutor (1983-1987), who felt there was a need to work more closely with parents. His experience in FE elsewhere had revealed a number of difficulties: the lack of contact with parents made it hard for staff to assess students' progress within the home, particularly in relation to coping skills and independence training; it seemed, though, that students had little opportunity to practice skills within the home; parents also felt a sense of isolation and were unsure about coping in the long term.

Parents needed to understand more about the course, staff needed to have a better understanding of home circumstances, and parents needed to meet each other to discuss issues of mutual concern and interest.

The course tutor also felt that parental contact tended only to occur when things had gone wrong. As a result, when staff and parents did meet it was in the context of a 'problem' and the atmosphere was often negative and antagonistic.

On the Linkways course, the parental role was seen as an important factor in the students' education; the college needed to understand the views of parents and parents needed to understand what the college was aiming to achieve.

The Farnborough PSG was set up with two main aims:

- to enable parents in a similar position to meet to discuss matters of mutual concern and interest, thereby reducing their sense of isolation;
- to enable the course tutor and parents to build a closer relationship whereby views and opinions can be openly exchanged, not only within the group but also on an individual level.

Preparation for parental involvement and organisation of the group

The preparation for parental involvement began at the time each student was referred to the college. In fact, when the parent support group was firmly established, the philosophy of active parental involvement was mentioned at the school leaver's interview. This philosophy was reinforced at every contact prior to the student starting at college.

During the first term, a well-attended parents' evening was held during which the idea of a parents' course was put forward. Parents supported the idea and a Parent Support Course was launched which met for ten weeks. By the end of the course, nine of the ten Linkways students had been represented at some point.

The course was one recognised by the college, with parents paying a nominal enrolment fee (£1 per parent). This strategy was adopted for two reasons: to help parents feel an accepted part of the college and to encourage them to attend; and to enable staff to claim the hours as part of their weekly class contact hours (rather than having to deal with the problems of claiming remission).

After the one-term course, parents requested a continuation and during the second year, they met fortnightly. There was a hard core of nine parents representing seven students, and overall twelve of the thirteen students were represented.

Content of the PSG meetings

During the first year, discussion topics included: the role of parents; the Linkways residential week; finance and money management; parental rights; conflict; letting go; post-Linkways; leaving home; and a discussion evening with support agency representatives (careers, schools and community health).

During the second year, when the PSG met fortnightly for all three terms, in addition to the topics mentioned above, the programme included sessions on: aims and objectives of the Linkways course; conflict at home and in college; sex education and personal relationships; Linkways leisure programme; the second year of the course; meeting the staff; what next (possible future options for students); a review of the PSG; and a review of the Linkways course.

Parents' attitudes and reactions

Initially, parents were unsure of their role and of whether they had anything worthwhile to say. They were generally lacking in self-confidence and tended to look to the course tutor for a lead.

However, sessions quickly turned into a self-help group, with parents exchanging experiences, fears, and expectations for their sons and daughters. They also began to see that they shared things in common.

The relationship between college and parents became a positive one; this was in contrast to the predominantly negative attitudes of those parents who did not attend the course.

Outcomes of the PSG initiative

Once the group was established, it became apparent that the main support was parent to parent — something which evolved quite naturally.

However, the PSG was also the catalyst for closer relationships between staff and parents. It enabled the course tutor to get to know parents as people and to begin to discuss previously hidden feelings. Issues of a personal and delicate nature would be raised and views openly shared and exchanged. Parents were also enabled to express their opinions about the course — both positive and negative.

The PSG offered a vehicle for those parents reluctant to become involved with the college. Because the group's existence became known outside the college, this also created the opportunity of reaching isolated parents (although the group's subsequent demise prevented this actually happening).

The PSG also developed a pressure group role, lobbying for the expansion of special needs provision; they were instrumental in having the Linkways course expanded from one year to two.

Other contact with parents

The course tutor operated an 'open door' policy whereby parents could either telephone or visit at any time. Home visits were also carried out where requested. The course tutor paid a home visit to each family before the start of each course.

Issues requiring further attention

- The need to involve parents at an earlier stage in the education system.
- How to reach the parents who did not attend the PSG.
- What form of post-course support should be offered to parents. They should not feel cut off when their sons and daughters are no longer attending college.
- The role of parents in curriculum development.

Postscript

The course tutor who has set up the PSG left the college in 1987 and the group subsequently folded. This raises an important issue: successful parental involvement of this kind may depend to a large extent on the support and commitment of college staff and management.

The views of one member of the PSG

One parent who belonged to the Farnborough PSG took part in the case-study interviews which form the main part of this report. What follows are some of his comments on why he found the experience helpful and where he feels improvements could be made in any future initiatives.

What helped:

- everyone sitting round in a circle with no 'teacher out in front';
- people talking with you rather than at you;
- being asked what you wanted to talk about;
- a tutor who organised the group and then 'took a back seat';
- being able to agree and disagree with one another;
- having a tutor who was committed and gave his time unstintingly;
- being able to meet in the place of their choice;
- being able to pool experiences with other parents;
- not being asked to 'give' anything;
- having informal times together in the pub afterwards;
- having some time on the course for social activities.

What could have been better:

- not all parents with students on the course attended;
- some parents did not feel confident enough to speak out freely;
- more support was needed from senior management.

South Thames College: a parent support group

Background

South Thames College in the Inner London Education Authority has been running courses for students with special needs arising from intellectual impairment for a number of years. In 1982, when the parents group described here was set up, there were three full-time courses for students with moderate or severe learning difficulties. There was also a one-year MSC-funded training workshop serviced by the college.

Aims and objectives

The support group was set up with the following aims:

- to bring together parents who were in a similar situation;
- to enable parents to discuss common problems and share coping strategies;

- to provide parents with relevant information and offer contacts with individuals and agencies who might be helpful to them.

The main focus of the group was the young person's transition from childhood to adulthood and the emotional and practical difficulties which could occur in families at this time.

Organisation of the group

Letters were sent out to parents explaining the aims of the proposed group and asking whether they would be interested in joining. Sufficient parents expressed an interest in the initiative and a second letter containing the programme of meetings was sent out. (This letter was sent to all parents, regardless of whether or not they had expressed an interest in participating.)

The organising team consisted of the course tutors from each of the three college courses, together with a social worker with extensive experience in group work.

The programme (see below) included some guest speakers, and other sessions were led by team members. However, during meetings the team members adopted an enabling, rather than a leadership, role and were careful not to dominate the discussions.

Meetings were held in the staff lounge, which was felt to be more comfortable and informal than a teaching room. There were eight Wednesday evening meetings, each lasting one and a half hours.

Attendance

Of the 35 students attending courses, ten were represented at some point during the parents' course. (None of the workshop students were represented, possibly because, in common with some of the course students, their disabilities were 'light', and parents may not have felt in need of support or felt it to be appropriate.) Overall, less than a quarter of those parents for whom the course was intended, did in fact take part.

Content of the meetings

The eight sessions covered the following topics: definitions and causes of learning disability; the development and sexual aspects of adolescence; new social and coping skills; employment and alternatives; leisure; problems of family life; family support; and an open forum.

Each meeting opened with about half an hour of semi-formal input followed by coffee and biscuits and about three-quarters of an hour of informal discussion.

Parents' attitudes and reactions

Parental attitudes varied considerable. At the start, there were some expressions of hostility from parents of young people labelled

'ESN(M)' who felt threatened by the idea that they might need such a group.

By the end of the sessions, attitudes had softened considerably and parents felt they had a far greater understanding of the way the college courses were intended to help students maximise their potential.

Some parents expressed dissatisfaction when they were not provided with 'the answers' to their difficulties. They were frequently unaware of their own expertise and strengths and felt that only the 'experts' had a contribution to make.

Outcomes of the initiatives

The group enabled some parents to express hitherto unshared feelings about their child and their relationshps with others. For example, one mother spoke about her feelings when her son with Down's syndrome was excluded from a family wedding invitation. Other parents were able to express their guilt about their child's disability and to have that guilt assuaged.

There was a much greater understanding amongst parents of the aims of the college course and their emphasis on students' transition to adulthood. Both parents and staff felt they had been able to get to know one another more fully than was possible in one-off meetings.

Parents received a great deal of specific information about DHSS allowances, and other agencies and their services.

Parents were able to meet others with similar difficulties. Some tentative friendships may have been formed but, at the very least, parents were able to meet the parents of their son's or daughters' friends.

Issues requiring further education

Despite the successful outcomes described above, three-quarters of the potential group members did not attend. The following strategies might help to overcome this problem:

- provision of transport for parents who have difficulties with travel;
- discussing the group with parents when they come for the initial interview;
- home visits by college staff or support from a social worker.

In future, parents should have more say in the content of the programme so that it focuses on areas of real concern to the parents involved rather than on those areas which college staff think should concern them.

The college needs to make a firm commitment to the concept of parental support and should not leave it to individual staff members to initiate activities such as support groups. Parent support groups should be an integral part of all courses for students with special needs.

An evaluation procedure should be established so that there is formal feedback from parents.

(This has been adapted from an article by Matthew Griffiths entitled 'South Thames College: A Parents' Support Group, the Initial Experience' in *Educare*, 17, pp 22-25.)

North Nottinghamshire College: a parent support group

Background

The Work Orientation Unit of North Nottinghamshire College of Further Education has been running courses for students with disabilities for a number of years. Between 1983 and 1985, the Unit undertook a specially funded action-based curriculum project, 'Transition to Adulthood' (TTA). (The results have been published in *Transition to Adulthood: A Curriculum Framework for Students with Severe Physical Disability*, FEU, 1986.)

The course, which catered for students with severe physical disabilities and associated learning difficulties, focused on six key areas:

- personal development
- personal care
- mobility
- basic education
- recreation
- work

Parents or guardians of all students enrolling on the TTA course are encouraged to be involved for the duration of their son's/daughter's course.

Reasons for developing parental support — aims and objectives

Some difficulties were encountered during the early stages of the project — particularly in relation to the financial independence of the students.

College staff felt that it would be beneficial for all concerned if parents could be encouraged to meet to discuss some of the issues stemming from the students' work.

Resources available for parental support

As well as input from college tutors, there is a part-time social worker appointed by the local Social Services Department to work with students and parents on the TTA course.

A full-time nurse, employed by the health authority, is a full-time staff member of the Work Orientation Unit, and is responsible for the personal care module of the TTA course.

Both the social worker and the nurse take part in parental support work (see below).

Arrangements for parents of first-year students

All parents are invited to attend the formal interview for the student's entry into the unit.

After a student has been accepted onto the course, both student and parents are invited to a two-day 'students' assessment programme', which is held at the end of each summer term before students enter college in September.

The programme for these two-day courses is organised by teaching staff, nursing staff and the social worker (see above). Parents of students who are already in college also contribute.

The mains areas covered during the two days are leisure, mobility, basic education, personal care and personal development.

Reaction to this programme has been very favourable and it appears to be a successful way of laying the foundations for a good relationship between parents and staff.

During the first year there are also informal parents' meetings held on a termly basis. These discussion groups give staff the opportunity to outline the course programme and development. Support services provide further input along with the social worker assigned to the course.

Parents are also able to meet staff to discuss the progress of individual students.

Arrangements for parents of second-year students

All parents are invited to individual meetings with the course tutors to discuss their son's or daughter's 'learning contracts'. Students are also invited to attend these meetings. Parents are offered a wide range of times and dates and appointments are made which meet individual parents' requirements.

Course tutors see students and parents, together with specialist careers officers, for a course interview.

As and when required, tutors do visit students' homes to discuss individual progress. The TTA social worker may well be involved in these visits.

Evaluation

The TTA team are currently evaluating the work undertaken during the academic year 1988/89, and experience suggests that there may well be a proposal to develop further work with parents.

Parents and self-advocacy: the views of some People First members

During the course of this study, the interviewer attended one of the monthly meetings of People First of London and Thames — a self-advocacy umbrella organisation for people with learning difficulties. During the meeting, members had a brief discussion about parents and self-advocacy. What follows is a summary of their discussions, which provides a further insight into parents and self-advocacy — from the perspective of the self-advocate.

Several of the self-advocates related how positive their parents were about their self-advocacy activities:

> 'My Dad things it's great ... thinks I'm getting on really well.'
>
> 'My Mum is interested ... likes what I am doing. Most of [my] relatives can understand the issues. My Mum understands I carry responsibility [as the Chairman of People First] and that we should fight for our rights.'
>
> 'My Mum thought it was a good idea.'
>
> '[My] parents think it's very good [that] I am speaking up for myself and doing the Treasurer's job [in People First].'

One or two people also mentioned the practical help and support their parents gave them. For example, one person talked about how her parents helped her with reading the minutes, agendas and other correspondence which she received for People First meeting.

At the same time, though, self-advocates were aware that parents could find it very hard to 'let go' and allow them to be more independent. As one person, who has moved into her own home, said: 'I know that now and again my Mum and Dad do miss me.'

Sometimes people could see that not moving away from home to live independently had its advantages and that living independently could be hard work. As one man remarked: 'My Mum and Dad want me to stay with them. And me? I want to stay with them because my Mum does all my washing and cooks all my meals!'

Sometimes, though, self-advocates' attempts to speak up and put forward their views to parents had not been well received:

> 'My friend's Mum has been very patronising. I tried to help [my friend] become more independent by helping him to get into a hostel but I got a letter from his father saying I wasn't to see him any more as they would look after him without help.'
>
> 'Parents from our club continually talk about us as "boys" and "girls". I have pointed this out to them and said that [we] can speak

for ourselves. It was a very cold response.'

'A lot of parents are the most awkward people because they wrap people up in cotton wool.'

One self-advocate had been asked to address a parents' meeting but had met an equally negative response:

'I went to a parents' meeting to talk about labels and they reacted very badly to me ... they wanted even worse labels than "mental handicap".'

As someone else pointed out though: 'It's difficult for parents to understand because they're not in the same situation [as us].'

One positive suggestion was made, however, about how some of these difficulties might be overcome. Self-advocates thought it would be useful if there were groups where parents could learn about self-advocacy and understand more of what it involved.

Appendix 1: Families and citizen advocacy: a brief case-study

Gareth is 35 years old and has Down's syndrome. He has three sisters and one brother, and his family come from a small Welsh town where Gareth has spent all his life.

When his brother and sisters grew up, married and left home, Gareth remained behind with his widowed mother. Apart from attending the local adult training centre, Gareth didn't go out very much and he and his mother spent most of their time at home in each other's company: their lives were very intertwined.

Gareth had learned to do quite a few things for himself; he could wash and dress unaided, although his mother usually shaved him. He could help his mother round the house with tasks like washing the dishes or drying up.

While his mother was alive, no firm plans were made about Gareth's future. His sisters had suggested that Gareth should come and live with each of them in turn, but Gareth's mother wasn't very keen on the idea so nothing came of that.

However, the local service-providing agency, set up under the All-Wales Strategy, had become involved with Gareth and his family. Someone from the agency came to visit every week and Gareth began to go out with them regularly. At the same time the agency suggested that maybe Gareth should move into one of the houses they were opening – but again nothing came of that, and Gareth remained at home with his mother until she died two years ago.

Immediately after her death, a care worker started coming to the house daily; she would arrive when Gareth came home from the training centre and stay until he went off again the next morning, helping him with household tasks and enabling him to remain in his own home. Meanwhile, the local service-providing agency was suggesting that Gareth might move to one of their houses.

Before she died, Gareth's mother had omitted to sign her will, so now the house, which Gareth still occupied, belong to all her five children. With the probability of Gareth moving to live elsewhere (although he had not been consulted about this) the family home was put up for sale.

No-one knew what Gareth was thinking until his sister Maureen went with him to see one of the houses where it was proposed he should go to live. Gareth refused to have any part in the proceedings, stating firmly that he already had his own place with his own carpets and curtains and he didn't need anywhere else to live.

It was at this point that Maureen realised that Gareth was trying to tell

them what he wanted, which was to stay in his own home, in the street he knew and with neighbours who he knew and who knew him.

To try and reach a decision about what should happen to Gareth a 'family meeting' was called. Gareth refused to participate, but Maureen did, and tried to persuade the rest of her family that Gareth should stay in his own home. She was outvoted by the others who wanted the sale of the house to go ahead. At this point Gareth tore down the 'For Sale' notice outside the house.

With this deadlock, what had been a family issue became a county court case – Gareth versus his brother, Jim. Shortly before the hearing though, the newspapers got hold of the story; as a result of the publicity, Jim decided to drop his case. An order was made in the county court, though, which now allows Gareth to remain in his own home for the remainder of his life.

The combination of Gareth's self-advocacy backed by Maureen's advocacy on his behalf has enabled Gareth to exercise his rights and make his own choice about where he lives. The care worker still comes in but Gareth is gradually learning to do more for himself. His neighbours are a good support too and everyone turned out for a 'housewarming' party for Gareth. As Maureen says, 'We've gained a whole neighbourhood'.

Appendix G.
Project Steering Group

Deborah Cooper, Director, Skill: National Bureau for Students with Disabilities (Chairperson of steering group)

Jacqui Christie, GLAD (Greater London Association for Disabled People)

Mariette Clair, Project Worker, RP449 Developing Self-Advocacy Skills through the Use of Portfolios with Long-term Unemployed Disabled People, FEU/REPLAN

Matthew Griffiths, Education and Training Advisor, MENCAP; Consultant RP510 UK contribution to OECD/CERI Disabled Action Programme

John Hersov, Freelance consultant and trainer in self-advocacy issues

Patricia Hood, Development Officer, Further Education Unit

Ed Manser, Special Needs Co-ordinator, Canterbury Council for Handicapped Children

Brian Simpson, Special Needs Co-ordinator, North Warwickshire College of Technology and Art

Carol Tennyson, North Nottinghamshire College of Further Education

Winifred Tumin, Chairman, Royal National Institute for the Deaf; Chairman, Independent Living Fund

Andrea Whittaker, Project Officer, King's Fund Centre; Advisor to People First of London and Thames